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Asthma is the most common chronic illness among children in the United States, and families who have a child with asthma face daily challenges to maintaining a normal family life. A descriptive, cross-sectional study was performed that studied four risk factors and four protective factors derived from the literature that impact these families, in order to better understand how nurses can meet the health care needs of the children with asthma and their families. Knafl's (1990, 1996) family management styles framework was applied as the theoretical framework of the study, and the concept of normalization was measured using the Family Management Measure (FaMM). The sample consisted of 43 parent dyads that had a child with asthma, who answered questions about their family, the child's asthma, and various dimensions of managing daily life with an ill child. Regression models were generated to determine the effect of the risk and protective factors on the outcome variable of normalization. The maternal and paternal scores on the FaMM were compared and were significantly correlated ($r = 0.532$, $p < 0.001$), while also exhibiting a significant difference in mean scores ($t = 2.73$, $p = 0.009$). The risk factor of asthma severity had a statistically significant effect on family normalization. Based on study findings, nurses should assess for differences between parents in managing their child's asthma. Also, nurses should increase interventions for the child who has severe asthma because the child and family are at increased risk for difficulty in achieving normalization. Recommendations are made to

perform studies that include children with other chronic illnesses and to include a wider variety of family configurations.

Key words: family, asthma, family management style, normalization

PARENTAL PERCEPTIONS OF FAMILY MANAGEMENT STYLES
IN FAMILIES WITH A CHILD WITH ASTHMA

by

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Approved by

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This project is dedicated to all families who care for a sick child.

APPROVAL PAGE

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CHAPTER I

INTRODUCTION

When parents receive a diagnosis of illness in a child, their experiences are individualized and fall across a wide continuum, from calm acceptance to paralyzing shock. Despite the extensive variation in family responses, feelings of stress and loss of control are commonly experienced by parents upon learning of a child's illness (Carpentier, Mullins, Chaney, & Wagner, 2006; Mishel, 1988). For very serious illnesses, parents frequently experience a period of shock, followed by denial, and continued worry and uncertainty (Wong & Chan, 2006). The family that manages a child's chronic illness on a daily basis is often exposed to unrelenting and increased levels of stress, which are significant risk factors for physical and/or psychological illness in all family members (Hayman, Mahon, & Turner, 2002; Honey & Halse, 2006; Murray, 2000; Williams, et al., 2002). While the family may appear to be coping effectively with this level of stress and may consider the stress to be a *normal* part of dealing with a chronically ill child, researchers have shown that this stress has detrimental effects on the entire family and decreases their ability to deal with additional stressors, such as family conflict and financial strain (Chiou & Hsieh, 2008; Frain, et al., 2007; McCubbin, 1997; McCubbin, Thompson, Thompson, & Furrell, 1999).

Researchers using the family management styles (FMS) framework have demonstrated that families who focus on what remains normal for their child and family, despite the child's illness, cope and manage their child's illness differently than parents who focus on the changes that the illness requires (Deatrick, Knafl, & Murphy-Moore, 1999; Knafl, Breitmayer, Gallo, & Zoeller, 1996; Knafl & Deatrick, 1990, 2002). Necessary changes for the family who has a child with asthma may include: making alterations to the environment to decrease asthma triggers, learning daily asthma management techniques, and living with the possibility of an asthma attack that will require emergent intervention (American Lung Association [ALA], 2010b; Morawska, Stalzer, & Burgess, 2008; National Heart Lung and Blood Institute [NHLBI], 2007). The ability to focus on the normal aspects of life is conceptualized as normalization (Deatrick, et al., 1999). As a result of normalization, families can achieve higher functioning with less negative effects on all members of the family despite caring for a chronically ill child (Knafl & Deatrick, 2006; Sharkey, 1995). Because the diagnosis of asthma in a child has potentially negative effects for the family's ability to maintain a normal family life, it is important for nurses to increase their understanding of this phenomenon. There is a lack of research examining the process of normalization and family management styles (FMS) among families who have a child with asthma, the most common pediatric chronic illness.

The study was guided by Knafl's (Knafl & Deatrick, 1990, 2003) theory of FMS because asthma impacts the entire family and needs to be studied from a holistic perspective. The theoretical framework is consistent with the family-centered care

model, which is the current standard for delivery of pediatric nursing care (Kratz, Uding, Trahms, Villareale, & Keckhefer, 2009; Wright & Leahey, 2005). In this chapter the framework for the study and the aims and research questions for the study are described. The key concepts are defined as they relate to the theoretical framework, and pertinent assumptions of the study are specified.

Purpose

The purposes of this study are to measure the maternal and paternal perceptions of normalization, defined as FMS, in families who have children with asthma and to determine the effect of specific risk and protective factors on FMS. Based on the literature, the following risk factors were identified: (a) child's gender, (b) child's race, (c) child's age, and (d) asthma severity. The following protective factors were indentified: (a) asthma education program for child, (b) asthma education for parent, (c) parent's past/current experience with asthma, and (d) care by an asthma specialist.

Significance of the Study

Chronic illness in children places added stressors on the child and the entire family (Englund, Rydstrom, & Norberg, 2001; Hopia, Paavilainen, & Astedt-Kurki, 2004; Saunders, 1999). Because both the child and family must learn to live with the illness, it is imperative that nurses study normalization in families who have a child with asthma and learn how to promote normalization by lessening the daily stress of disease management for these families. Nurses foster self-care and empower families to thrive

within the constraints of a stressful environment related to their child's illness. While a chronic illness is a definite family stressor, knowledge gained about risk and protective factors will help guide nursing interventions that promote normalization for this population.

There has been little reported on the impact of asthma on family management and the subsequent consequences for children and families. Based on a review of the literature related to caring for a child with a chronic illness, it became increasingly evident that nurses need a deeper understanding of the multi-faceted phenomenon of families who are living with a child who has asthma. The significance of the study was to determine if identified risk and protective factors had an effect on normalization in families who care for an asthmatic child. Knowledge gained from this study can be used by nurses to improve the quality of care for children and their families. For example, nurses can individualize patient education offerings based on the severity of the child's asthma and can measure outcomes for families using FMS as an indicator of normalization and successful family functioning. Better understanding of the families' experience of living with asthma and facilitating effective management of the child's chronic condition will have both immediate and long-term effects toward normalization for the family and health promotion for all its members.

Background

The face of chronic illness is changing; it is no longer a phenomenon that occurs at the end of life, affecting primarily the elderly and lasting only a few years. From the

most recent National Survey of Children's Health, over 16 million children (15-18% of children) have chronic conditions (The Centers for Disease Control and Prevention [CDC], 2007.). More concerning is that these statistics represent an increase from the previous 10% prevalence rate of chronic illness in children only seven years ago (CDC, 2007). From the current standard of family-centered care, it is imperative that nurses gain a better understanding of families who have a child with chronic illness. Dealing with a chronic illness on a daily basis presents different challenges for families than those faced by families whose children may have self-limiting conditions or acute illnesses. The short-term and long-term effects of living everyday with a chronic condition for both the child and family are not well understood nor well explicated in the literature.

Asthma

Asthma is the most common chronic pediatric illness and affects over 7 million of our nation's children and their families (ALA, 2010b; CDC, 2009). More specifically, in North Carolina (NC) 10% to 17% of children have asthma, and another 17% have the condition but are undiagnosed (North Carolina Division of Public Health, 2006). The statistics are compelling on both the national and state levels and have consequences for the child and family. Breathing problems are usually episodic, inferred by the term, asthma attack. However, the underlying causative inflammation is a continuous and chronic condition. Many people are not aware of the necessity of daily management of inflammation caused by asthma (ALA, 2010a; Dozier, Aligne, & Schlabach, 2006; Werk, Steinbach, Adams, & Bauchner, 2000). Numerous patients and their families continue to view asthma as an acute condition that only requires treatment for acute attacks. Because

the illness may not manifest itself on a daily basis, the adherence to a daily regimen of preventative care may be very difficult for children and families. *Healthy People 2010* guidelines state that better management of asthma based on established guidelines will greatly reduce health problems related to the condition (The United States Department of Health and Human Services, 2000). Revisions to the current 2010 guidelines for *Healthy People 2020* include recommendations for children to have current asthma action plans and to receive quality patient education in order to improve outcomes (United States Department of Health and Human Services, 2009). Because better asthma symptom control is associated with positive outcomes in children, specifically better school attendance (Gerald, et al., 2006; Levy, Heffner, Stewart, & Beeman, 2006; Moonie, Sterling, Figgs, & Castro, 2006) and fewer emergency room visits and/or hospitalizations (Levy, et al., 2006), it is important to facilitate an optimal asthma management plan for each child. Many nurses are in daily contact with children who have asthma, and they may have multiple opportunities to intervene in the management of this condition. Nurses may also be able to promote normalization in families as they care for their asthmatic child.

Asthma classification and treatment guidelines have undergone recent changes. In 2007, the National Heart, Lung, and Blood Institute (NHLBI) released new recommendations for treatment based on the frequency of symptoms. Asthma is now classified as: (a) mild intermittent, (b) mild persistent, (c) moderate persistent, or (d) severe persistent (NHLBI, 2007). This classification is based on the frequency of events in the following categories: (a) asthma symptoms, (b) nighttime awakenings, (c) short-

acting beta agonist use, (d) interference with activities, (e) lung function, and (f) exacerbations (NHLBI, 2007). For the child with intermittent asthma, there may be rare interferences with activities, and asthma symptoms are present less than two days per week. At the other end of the continuum, the child with severe asthma has persistent symptoms, and activities are extremely limited. As asthma severity increases, there is the potential for a greater negative impact on the child and family. Fortunately, most asthma in children is categorized as mild to moderate, and only 10% of asthma in children is considered severe, based on the new criteria (ALA, 2010b). However, these severe cases represent a disproportionate amount of the mortality and cost statistics related to this condition (ALA, 2010b; NHLBI, 2007). Asthma in a child represents a threat to the family's ability to provide a normal family life for each of its members. In order to better understand how families normalize their family situations under these circumstances, risk and protective factors for families who have a child with asthma were identified. The relationship of these factors to normalization was depicted in the model that provided a conceptual framework for the study and is described in the next section.

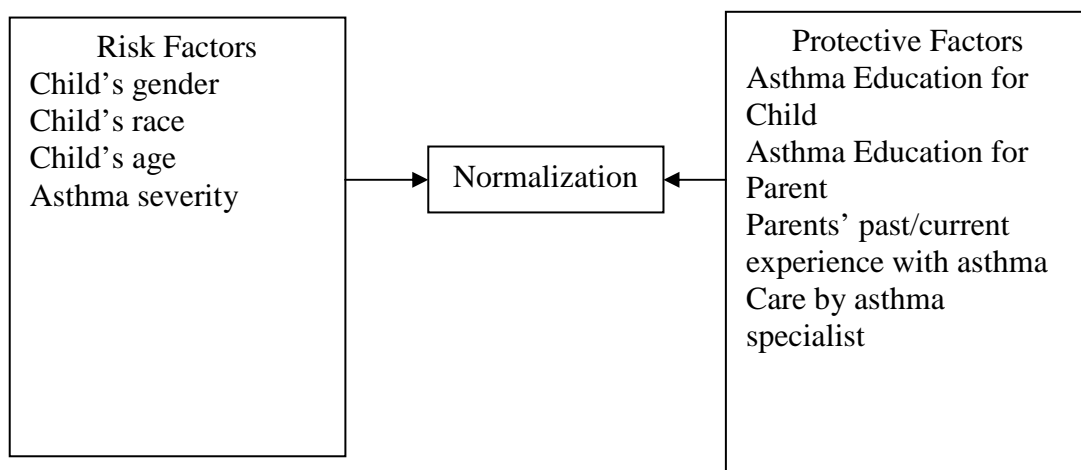
Risk and Protective Factors Model

A risk and protective framework serves as the conceptual basis for this study. Normalization and the FMS of the family are influenced by a variety of personal and environmental risk and protective factors. Certain factors may have increased the risk of a poorer FMS such as: (a) male gender (CDC, 2009), (b) race (Diette & Rand, 2007; Gehlert, et al., 2008; Smedley, Stith, & Nelson, 2003), (c) child's age (Barton, Sulaiman, Clarke, & Abramson, 2005; Carderelli, 2009; Federal Interagency Forum on Child and

Family Statistics, 2008), and (d) asthma severity (Kelley, Mannino, Homa, Savage-Brown, & Holguin, 2005; Knafl & Deatrick, 2006; Moonie, et al., 2006). Factors that may have a protective effect on the child and family and thus promoted a more optimal FMS are: (a) asthma education programs for children and/or parents (Brown, et al., 2005; Kratz, et al., 2009; Winkelstein, et al., 2006), (b) parents' past and/or current personal experience with asthma (Coffey, 2006; Maltby, Krisjanson, & Coleman, 2003; White, White, & Fox, 2009), and (c) access to care by a specialist (Peterson-Sweeney, 2009; Smedley, et al., 2003). The following figure depicts the conceptual framework based on risk and protective factors identified for inclusion in the study. The effect of these factors on normalization and FMS were studied.

Figure 1

Conceptual Model of Factors Predictive of Normalization as reflected in FMS for Families with a Child with Asthma



Risk Factors

While each family has an individualized response to their child's chronic illness, several identified risk factors are related to poorer outcomes within this population. The child's gender, race, and age are demographic characteristics related to an increased prevalence of asthma and potentially negative effects on the family members' abilities to lead normal lives. Severity of the child's asthma also is a potential risk factor that was investigated in the study.

Child's Gender and Race

There are unequal rates of asthma prevalence based on the child's gender and race, which make the influence of these factors on normalization and FMS an important component to investigate in the study. Males are more likely to have asthma, with a rate of 15% among males, as compared to an 11% rate among females (CDC, 2009).

Disproportionate numbers of minority children have asthma. The prevalence rate for African Americans boys (20%) and girls (15%); Hispanic boys (13%) and girls (9%) exceeds that of White boys (11%) and girls (7%) (CDC, 2009). Minority families may have several children with asthma with a resulting exponential increase in the caregiver burden and difficulty with achieving normalization (Akinbami, Flores, & Morgenstern, 2006; Fiese, Winter, Anbar, Howell, & Poltrock, 2008; North Carolina Division of Public Health, 2006). With disparate asthma prevalence rates across racial groups, there may be differences in normalization for families based on this risk factor.

Child's Age

Age and corresponding developmental level of the child often inversely corresponds to the level of caregiver burden (Barton, et al., 2005; Fiese, et al., 2008). The child's age and developmental level also are indicative of the amount of independence in self-management that the child may safely assume (Zebracki & Drotar, 2004). Because over half of all cases of asthma begin before the age of 10 (Guthrie & Trigen, 2002), the family may incur years of daily stress related to managing a chronic illness for the child, which may be reflected in FMS. Normalization may be affected by the child's age and may be more difficult for families who care for a very young child with multiple care needs or have cared for a child with asthma for an extended length of time.

Asthma Severity

It has been well explicated in multiple studies that having a sick child is a stressor for the entire family (Chiou & Hsieh, 2008; Frain, et al., 2007; McCubbin, et al., 1999; Svavarsdottir, Rayens, & McCubbin, 2005), but there was no clear agreement if the severity of illness impacts the level of stress. It is not known if there is a relationship between the seriousness and/or severity of a child's illness and the resulting negative effects on daily family life. Specifically, it is not known if the family's ability to achieve normalization is impacted by the severity of their child's asthma.

Protective Factors

In contrast to risk factors that may impair the family's ability to normalize, there are protective factors that may promote normalization for the family with a child with asthma. For this study, several factors were examined as potential protective factors. First, care by an asthma specialist may promote better asthma outcomes and parent satisfaction. Next, asthma education for children and their parents may have a positive effect on the family's ability to manage their child's asthma. Lastly, parents who have past or current experience managing their own asthma may have improved capabilities to care for their child with asthma.

Care by an Asthma Specialist

The first protective factor is access to care by specialists for the child's chronic illness. While the preventative and acute episodic health care needs of children may be managed adequately by primary care providers, researchers have found that children who receive additional coordinated care from specialists experience better health outcomes, and parents are also more satisfied with the care their child received from specialists (Anderson & Fite, 1993; Smedley, et al., 2003). It is not known if receiving regular care from an asthma specialist will assist the family to achieve normalization for all its members.

Participation in an Asthma Education Program

Access to information about the child's condition decreases stress for the sick child and family (Hanson, Gedaly-Duff, & Kaakinen, 2005; Wright & Leahey, 2005). The

child's developmental level and the family's current knowledge of the child's asthma management regimen are pertinent factors that affect the family's need for teaching. Receiving individualized patient education related to asthma education may provide information that integrates asthma management into the family's daily life and therefore assists the family towards normalization. Appropriately planned and delivered patient education may also assist families towards normalization by decreasing stress related to caring effectively for their child on a daily basis. Unintentionally overloading the family with information will actually increase stress and impair their ability to cope with their child's illness (Hanson, et al., 2005; Winkelstein, et al., 2006; Wright & Leahey, 2005). Therefore, it is important to gain understanding of the impact of asthma education on family normalization.

Child's participation in an asthma education program. Asthma education for children often occurs in school settings, and multiple studies support that school nurses' interventions positively impact the family's ability to cope with a chronic illness (Anderson, et al., 2005; Bartholomew, et al., 2006; Svavarsdottir, et al., 2005; Telljohann, Dake, & Price, 2004). School-based asthma education programs may be implemented via a standardized curriculum, such as the multi-session *First Aid for Asthma* (Shaw, Marshak, Dyjack, & Neish, 2005) or *Open Airways* programs (Anderson, et al., 2005). Robinson and colleagues implemented an innovative program by adding literacy and self-efficacy components to the 6-week *Open Airways* asthma education program (Robinson, Calmes, & Bazargan, 2008). Gerald, Redden, Wittich, Hains, and Turner-Henson (2006) conducted an evaluation of a school-based asthma management program and concluded

that children had significantly increased knowledge of asthma post- intervention.

However, no significant decrease in school absences, emergency department visits, and hospitalizations were observed among children who participated in the study (Gerald, et al., 2006). Children may receive asthma education in the clinic setting in a group or through an individualized format. When asthma education is delivered to a child and family, the nurse is able to tailor interventions to meet their specific learning needs and can offer teaching that is culturally appropriate (Fisher, Burnet, Huang, Chin, & Cagney, 2007). The home setting is another venue in which the nurse can focus on the learning needs of one family and offer a standardized curriculum with an individualized approach (Brown, et al., 2005). While asthma education programs for children have had positive outcomes, it is not known if the child's participation in these programs is related to the family's improved ability to achieve normalization.

Parent's participation in an asthma education program. While asthma education programs for children have been described and evaluated in the literature, only one study included parents in an asthma education program (Brown, et al., 2005). This program was for very young children with asthma and was met with many obstacles to successful implementation. Specifically, the nurses encountered difficulty with: (a) scheduling appointments with the mothers, (b) mothers not being home for scheduled appointments, (c) mothers frequently rescheduling appointments, and (d) mothers' lack of acceptance of the nurses and the importance of the education. It is critical to measure the effect of asthma education for parents on FMS because increased information about asthma management has been shown to promote better asthma outcomes (Clayton, 2005; Shaw,

et al., 2005). Specifically, it is important to determine if the parent's participation in asthma education is related to the family's ability to achieve normalization.

Parent's Past/current Experience with Asthma

Based on the literature, parents who have had positive experiences with self-management of their own asthma as a child may be better equipped to manage their child's illness (Coffey, 2006; Holm, Patterson, Rueter, & Wamboldt, 2008; Kratz, et al., 2009; Sallfors & Hallberg, 2003). However, if the parents had negative experiences with either their own illness, or caring for a sick family member, it is likely that this may transfer into their adulthood and influence their approach to their child with asthma. A parent who also has asthma may have an empathetic understanding and increased care competence, but it is not known if these attributes transfer to attaining normalization as reflected in a more positive FMS (Finley & Mira, 2008; Maltby, et al., 2003). Additionally, it is not known if parents who have past or current experience with their own asthma management are able to achieve normalization while caring for their child with asthma.

Potential Detrimental Consequences of Asthma for the Child and Family

The consequences of having a child with asthma may be negative for both the child and other family members. Several potential negative consequences related to childhood asthma are examined. First, each school absence is a missed opportunity for a child to learn and develop (Levy, et al., 2006; Telljohann, et al., 2004). Also, a child who has

frequent illnesses is at risk for problems with school performance and delays in normal development because school provides a supportive environment for a child to meet developmental milestones (Rehm & Bradley, 2005; Tara & Potts-Datema, 2005). Next, children who have asthma frequently require care from emergency departments and inpatient care settings, which has implications related to: (a) cost of care, (b) coordination of care, (c) school absences, and (d) parents' lost work time and wages (Laster, Holsey, Shendell, McCarty, & Celano, 2009; Sin, Svenson, Convie, & Man, 2003; Watson, et al., 2009). Lastly, stress levels for the entire family are often increased when a child has asthma (Chiou & Hsieh, 2008; Davis, Davies, Waters, & Priest, 2008; Hoff, et al., 2005; Svavarsdottir, et al., 2005).

School Absenteeism

Chronic illness causes disruption in a child's ability to perform daily tasks and is responsible for increased school absenteeism rates ("Children with chronic illness," 2008). For all children, asthma is the leading cause of school absenteeism. Asthma accounts for nearly 20 million lost school days each year, or an average of 7.6 days of school nonattendance for each child with asthma (ALA, 2010b; Telljohann, et al., 2004). School attendance is a vital and formative aspect of a child's life (Mitchell, Adams, & Murdock, 2005; Moonie, et al., 2006; Telljohann, et al., 2004). Increased absenteeism may result in poor school performance and achievement in the short-term and may also be linked to long-term effects such as lower education opportunities and decreased lifetime earning power (Telljohann, et al., 2004). When the child has excessive school absences, the family's ability to achieve normalization may be negatively affected

because the benefits of regular school attendance are not provided for the child and family.

Academic and Developmental Delays

Regular school attendance is essential for academic success, and poor school attendance is linked to problems, such as lower grade achievement and poor self-concept (Moonie, et al., 2006; Telljohann, et al., 2004). From a developmental perspective, success in school is the cornerstone of successful maturation. For the school-age child, mastery in the school environment is the primary method for successfully resolving the psychosocial crisis of Erikson's (1950) stage of *industry versus inferiority*. The child obtains a sense of competence and self-esteem that is vital for future growth (Erikson, 1950). For the adolescent, the child is in the stage of *identity versus role confusion* and is developing a healthy self-image (Erikson, 1950). For a teenager with asthma, this developmental milestone involves the integration of having a chronic illness into the youth's definition of self. When a child is not meeting developmental milestones at the expected time intervals, the family's normalization may be negatively affected because family life must be altered to meet the child's needs.

Emergency Department Visits and Hospitalizations

Access to adequate health care from primary care providers and specialists has been identified as another protective factor. When a child with a chronic illness does not receive consistent preventative family-centered care, the need for episodic and fragmented emergent care and/or expensive hospitalization is significantly increased

(Diette & Rand, 2007; Miller, 2000). Fragmentation of care is associated with poor asthma outcomes for the child that may lead to increased stress for the entire family (Diette & Rand, 2007; Levy, et al., 2006). Emergency department visits and hospitalizations pose a threat to normalization for the family with a child with asthma because daily routines are disrupted, and time must be focused on the child's illness. Families who do not receive quality health care for their child with asthma may have more difficulty with normalization because the child has poorer health outcomes that disrupt normal family life.

Family Stress

The family that manages a child's chronic illness on a daily basis is exposed to unrelenting and increased levels of stress, which is a significant risk factor for physical and/or psychological illness in all family members (Hayman, et al., 2002; Honey & Halse, 2006; Murray, 2000; Williams, et al., 2002). While families may appear to be coping effectively with high levels of stress, they incur the effects of cumulative stress that decrease their ability to deal with concurrent stressors, such as family conflict and financial strain (Chiou & Hsieh, 2008; Frain, et al., 2007; McCubbin, 1997; McCubbin, et al., 1999). Increased stress on the family may lead to poor family communication and loss of family integrity due to impaired coping. Families who are under higher levels of stress may be less able to achieve normalization.

Researchers have demonstrated the importance of family involvement in the management of any chronic illness affecting a child (Bartholomew, et al., 2006; Boling, 2005; Coffey, 2006; Moonie, et al., 2006). More specifically, asthma poses daily stress

for millions of families (ALA, 2007; Svavarsdottir, et al., 2005) and has potentially detrimental effects on the child and family regarding quality of life (Clayton, 2005; Shaw, et al., 2005), depression (Boling, 2005), psychological distress (Saunders, 1999), self-concept for the child (Chiou & Hsieh, 2008), school performance (Anderson, et al., 2005; Moonie, et al., 2006; Telljohann, et al., 2004), and caregiver burden (Barton, et al., 2005; Fiese, et al., 2008). Researchers in several studies support that nurses' interventions have a positive impact on the family's ability to cope with a chronic illness (Anderson, et al., 2005; Bartholomew, et al., 2006; Svavarsdottir, et al., 2005; Telljohann, et al., 2004). Researchers in the area of family coping support that increased family resources are related to improved family functioning (Chiou & Hsieh, 2008; McCubbin, Thompson, & McCubbin, 1996; Svavarsdottir, et al., 2005). When families have the adequate resources to manage their child's asthma and do not feel overly stressed by care demands, they may be better able to achieve normalization.

Theoretical Foundation

The FMS framework was developed by Knafl and Deatrick (1990; 1996), and was based on the concept of normalization from the discipline of sociology (Rodgers & Knafl, 2000). In the original concept analysis of normalization, four defining criteria were identified: (a) acknowledging impairment, (b) defining family life as normal, (c) defining minimal social consequences due to the impairment, and (d) participating in behaviors that demonstrate normalcy (Knafl & Deatrick, 1990). These attributes were revised and expanded to include a fifth defining criterion, the development of a treatment regimen

that was consistent with a normalcy lens (Knafl & Deatrick, 2002; Rodgers & Knafl, 2000).

The concept of normalization was further developed as a part of a study that asked the simple question, “How do families respond to a child’s chronic illness?” This was a qualitative study of 200 families with chronically ill children. From this large study, five distinct family management styles emerged as distinct patterns of everyday family life: (a) thriving, (b) accommodating, (c) enduring, (d) struggling, and (e) floundering (Knafl, Deatrick, & Gallo, 2008; Rodgers & Knafl, 2000).

The three interdependent components of the FMS framework (FMSF) are: (a) definition of the situation, (b) management behaviors, and (c) perceived consequences of all family members (Knafl, et al., 2008). FMS takes into account the mutually-dependent effect of these components for each family member within the larger sociocultural context. FMSF provides a holistic view of the family and its ability to achieve normalization, which is the family’s definition of their lives as essentially normal, despite having an ill child (Deatrick, et al., 1999; Knafl & Deatrick, 1990; Knafl & Deatrick, 2006). Normalization is both a process and an outcome; it is an effective coping mechanism that allows families to define their lives as essentially normal, despite the care demands of an ill child, and it is the family’s perception that they are effectively providing a normal family life despite their child’s illness (Deatrick, et al., 1999; Knafl, Darney, Gallo, & Angst, 2010; Knafl & Deatrick, 2002). This study was guided by Knafl’s (1990, 1996) theory of FMS because asthma impacts the entire family, and it was essential to study this phenomenon from the family’s perspective. Using the FMSF, the

impact of the risk and protective factors on family normalization in families with a child with asthma was investigated.

Specific Aims and Questions

The specific aims and corresponding research questions are listed below.

Aim (1): To determine the families' levels of normalization, defined as FMS, and operationalized as the FaMM Scale score, in families with a child with asthma.

Q1: What are the family FaMM scores, based on the maternal and paternal FaMM scores, of families who have a child with asthma?

Aim (2): To explore the relationship among several variables: (a) child's gender, (b) child's race, (c) child's age, (d) asthma severity, (e) child's participation in an asthma education program, (f) parent's participation in an asthma education program (g) parent's past/current experience with asthma, and (h) care by an asthma specialist on the variable, family normalization, defined as FMS, and operationalized as FaMM score, of families who have a child with asthma.

Q2: What is the influence the potential risk factors of : (a) child's gender, (b) child's race, (c) child's age, and (e) asthma severity on the variable, family normalization, defined as FMS, and operationalized as FaMM score?

Q3: What is the influence of the protective factors of the: (a) child's participation in an asthma education program, (b) parent's participation in an asthma education program, (c) parent's past and/or current experience with asthma, and (d) care by

an asthma specialist on the variable, family normalization, defined as FMS, and operationalized as FaMM score?

Aim (3): Compare the maternal and paternal perceptions of normalization, defined as FMS, and operationalized as FaMM score, in families who have a child with asthma.

Q4: What is the relationship between maternal and paternal perceptions of normalization, defined as FMS, and operationalized as FaMM score?

Q5: What is the difference in parent's perceptions of normalization, defined as FMS, and operationalized as the mean maternal and paternal FaMM scores in families who have a child with asthma?

Q6: What are the maternal and paternal perceptions of normalization, defined as FMS, and operationalized as the six subscale scores of the FaMM?

Q7: What is the relationship between maternal and paternal perception of normalization, defined as FAM, and operationalized as the scores on the six subscales of the FaMM?

Q8: What is the difference in maternal and paternal perceptions of normalization, defined as FMS, and operationalized as the mean scores on the six subscales of the FaMM?

Definitions

The following definitions for concepts and constructs are utilized for this study

- 1) *Family* is defined as a child and two parents who partner in the parenting and asthma management. Both parents must live in the same household with the

child. A family living with asthma is a family who has at least one child, aged 1-18, and self-identifies a current diagnosis of asthma by a health care provider. It was reasonable to accept the parent's validation of the diagnosis, based on prior studies (Englund, et al., 2001; Moonie, et al., 2006; Perry & Ireys, 2001).

- 2) According to the American Lung Association, asthma is defined as, "a chronic inflammation of the airways with reversible episodes of obstruction, caused by an increased reaction of the airways to various stimuli" (ALA, 2010a).
- 3) Risk factors are defined as "those variables associated with a higher likelihood of undesirable outcome" (Allen, 1998, p. 57).
- 4) *Protective factors* are defined as the "absence of risk...exerting direct effect on outcome and...effectiveness may differ according to the child's developmental level or sex" (Allen, 1998, p. 57).
- 5) *Child characteristics* are defined as the child's age, race, and gender. The child characteristics are operationalized as the parents' answers to these questions on the Asthma Information Survey (AIS).
- 6) Specific protective factors are defined as follows:
 - a) *Parent's past/current experience with asthma*: The parent's self-reported experiences of having asthma as a child or having a current diagnosis of asthma as reported on the AIS.
 - b) *Care by an asthma specialist*: The parent's self-report of receiving care from a specialist for their child's asthma as indicated on the AIS.

- c) *Child's participation in an asthma education program:* Any school-based asthma education program or individualized teaching in a health care setting related to the management of the child's asthma. This information was self-reported by the parent on the AIS. Data regarding specific characteristics of the program, such as setting and length, were collected. Brief interactions with nurses were not considered participation in an asthma education program.
- d) *Parent's participation in an asthma education program:* Any school-based asthma education program or individualized teaching in a health care setting related to the management of the child's asthma. This information was self-reported by the parent on the AIS. Data regarding specific characteristics of the program, such as setting and length, were collected. Brief interactions with nurses were not considered participation in an asthma education program.
- 7) Normalization is defined as the family's definition of their lives as essentially normal, despite having a sick child (Deatrick, et al., 1999; Knafl & Deatrick, 1990; Knafl & Deatrick, 2006). Normalization is defined by the FMS of the family. Each family's FMS is operationalized using the Family Management Measure (FaMM), a 53-item scale for parents. Parents responded to statements using a 5- point Likert scale that incorporated the eight conceptual dimensions of the FMSF and measured parents' perceptions of their child's everyday life. The FaMM is divided into 6 subscales that measure the following areas of FMS: 1)

child's daily life, 2) condition management ability, 3) condition management effort, 4) family life difficulty, 5) view of condition impact, and 6) parent mutuality. Higher scores on three of FaMM subscales (child's daily life, condition management ability, and parent mutuality) indicate greater ease with normalization and in managing their child's asthma. Higher scores on the remaining subscales (condition management effort, family life difficulty, and view of condition impact) are indicative of greater difficulty with normalization and with managing their child's asthma. Both maternal and paternal perceptions of the FMS were measured to determine normalization for the family.

- 8) *Asthma severity* was based on the 2007 NHLBI Guidelines (NHLBI, 2007) and based on frequency of asthma symptoms as reported by parent as: *mild intermittent, mild persistent, moderate persistent or severe persistent*. The specific frequencies for daily asthma symptoms were provided on the demographic tool, and parents marked each applicable area. The researcher determined the specific asthma category, based on parent's report of symptom frequency.

Assumptions

The assumptions for this study are identified in this section. First, it is assumed that the FMS framework (Alderfer, 2006; Knafl & Deatrick, 2006; Ogle, 2006) is an appropriate conceptual model for studying families who have a child with asthma. It also is assumed the concept of normalization could be measured and operationalized by the

FaMM scale (Knafl, 2009). Another assumption is that the parent is the appropriate person to describe normalization, defined as FMS, for the family and that input from the child regarding normalization was not developmentally appropriate and potentially invalid because the FaMM was developed for use with adults only (Knafl, 2009). It also is assumed that normalization, defined as FMS, and operationalized as the FaMM score is a perception of paramount importance in the management of a child with asthma and provides valuable information in the planning of individualized nursing care for these children and their families. Additionally, it is accepted that parents respond truthfully to questions about living with a child who has asthma. Lastly, it is assumed that the data collected reflect the reality of life experiences for the families living with a child who has asthma.

Summary

The underpinnings for the study that examines the relationship of variables on normalization, operationalized as FMS, in families living with a child who has asthma have been presented in this chapter. The conceptual framework of FMS, within a larger paradigm of risk and protective factors, has been explicated. The aims and research questions for the study also have been delineated. Definitions of the concepts and assumptions germane to the study also have been included. A review of the literature of studies that have investigated the impact of chronic illness on families is provided in chapter two.

CHAPTER II

REVIEW OF LITERATURE

Many families experience stress while meeting everyday responsibilities of children's school, extracurricular activities, and family endeavors. However stress for the family greatly increases when one of the family members is a child with a chronic illness ("Children with chronic illness," 2008; Murray, 2000; Svavarsdottir, et al., 2005). Current literature related to chronic illness in asthmatic children will be presented in this chapter, and the state of the science related to specific factors that impact the family with a child with asthma are evaluated. An in-depth understanding of the factors that affect families with a child with asthma is essential for nurses to help families better manage the child's condition. The theoretical framework for the study, normalization, and FMS were evaluated for use with this specific population (Knafl & Deatrick, 2002; Knafl, et al., 2008).

Chronic Illness in Children

As families enter the childbearing phase, a common response from the expectant family is, "We don't care if it's a boy or a girl, just so it's healthy." For almost 20% of families (CDC, 2008; "Children with chronic illness," 2009), this ideal expectation of family life with a healthy child will not be true. Nurses are in key positions to assist families who must reconcile their hopes and dreams with their lived reality. While all

areas of nursing practice value the family and its impact on the delivery of quality health care, the child is totally dependent on the family to meet their needs of daily regimens and to gain access to health care when needed (Boling, 2005; Bomar, 2004; Wu, Smith, Bokhour, Hohman, & Lieu, 2008). Therefore, family-centered pediatric care strives to support the entire family as the recipient of care in order to meet the needs of the chronically ill child and family.

The concept of chronic illness in children is a relatively recent phenomenon in nursing. Pediatric health care, including nursing care, has historically focused on well child care, immunization, and injury prevention/health promotion anticipatory guidance (Bomar, 2004; Hayman, et al., 2002; Kratz, et al., 2009). While these components of care continue to be priorities for providers in the field of family-centered care, and pediatric nursing in particular, there is a growing need for coordinated health care for children with chronic illness. Health care needs of children with chronic illness are different from the needs of a healthy child. For example, children with a chronic illness require care from specialists along with regular, preventative care from a primary care provider. Care for a child with a chronic illness is often complicated and costly, requiring coordination of services and communication among many providers. The increasing numbers of children with a chronic illness have led to a paradigm shift in the delivery of pediatric care (Coffey, 2006; Hayman, et al., 2002; Hopia, et al., 2004; Kratz, et al., 2009). Previously, family-centered care focused on episodic visits for acute conditions and annual well-child examinations. However, for millions of chronically ill children, primary care must be coordinated with specialty services to promote positive

outcomes. Improved coordination of care at the system level may decrease the stress of accessing quality health care for families.

Chronic illness in children places added stressors on the child and the entire family ("Children with chronic illness," 2008; Englund, et al., 2001; Hopia, et al., 2004; Saunders, 1999). Because both the child and family must learn to live with the illness, it is imperative that nurses study this aspect of the phenomenon and learn how to lessen the negative impact of disease management regimens for these families. When nurses know about the family and the daily lives of its members, they are able to provide individualized support to the family to achieve normalization (Jokinen, 2004). Nurses foster self-care and empower families to have normal family lives, despite the constraints of increased stress imposed from their child's illness. While chronic illness is a definite family stressor, therapeutic interventions may lessen its effects on the child and the disruption to a normal family life.

Chronic illness has a wide range of effects on the individual child and on their families. The reaction to a diagnosis of a chronic illness may be the family's perception of a minor inconvenience in which slight changes are necessary in the family's daily routine to manage the child's condition. In contrast, the child's illness may constitute a major crisis for all family members, as they provide daily care for a sick child. Most families have a reaction that is between these two extremes and is often mercurial in nature (Hoff, et al., 2005; Svavarsdottir, et al., 2005; Wright & Leahey, 2005). The continuum of responses is dependent on many factors, including: (a) the specific illness, (b) the complexity of the daily regimen, and (c) the necessity of frequent medical

attention and hospitalization (ALA, 2010b; Children with chronic illness," 2008; Jenkins, et al., 2003). On an individual level, the child may feel different from his peers and thus, experience isolation and depression (Boling, 2005; Chiou & Hsieh, 2008; Saunders, 1999). The child's age and developmental level are partially predictive of his or her understanding of the illness and coping abilities (Bartholomew, et al., 2006; Children with chronic illness," 2008).

From the developmental perspective, the impact of chronic illness is influenced by the child's age and corresponding developmental level. The school-age child, ages six through twelve, is in Erikson's (Erikson, 1950) fourth development stage of *industry versus inferiority*. A chronic illness may prevent the child from meeting the developmental milestones for this age, leading to both immediate and delayed negative consequences. It is crucial for the child to develop a sense of achievement and competency, or the negative consequences of feelings of worthlessness may result. In this developmental stage, it is important to have successes in structured activities and to gain social skills within a peer group (Erikson, 1950). Unfortunately, these developmental successes can be inhibited by medical care regimens. Daily care routines are often time-consuming and interfere with the child's ability to participate in school and extracurricular activities (Asthma and Allergy Foundation [AAF], n.d.; Englund, et al., 2001; Fiese, 2008; Fiese, et al., 2008). For example, the child with asthma triggered by allergens and/or exercise may be prevented from playing certain popular sports, such as soccer, football, and golf. Asthma, the most common cause of school absenteeism (ALA, 2010b; AAF, n.d.; Moonie, et al., 2006; Telljohann, et al., 2004) decreases time in the

school setting, where the child can best achieve the developmental milestone of industry for this age.

The adolescent child, ages thirteen through eighteen, is impacted differently from a developmental perspective by having a chronic illness. For an adolescent, the child is in Erikson's *identity versus role confusion* stage of development (Erikson, 1950). In this stage the developmental tasks are to obtain clear individuality and separateness from one's family of origin and to begin to form a philosophy of life (Erikson, 1950). Social interactions with peers are imperative to surmounting these milestones successfully, and the responsibility of managing a chronic illness may impinge on these peer relationships. For example, the teen with asthma may need to avoid asthma triggers, such as pet dander, and therefore cannot safely visit in a friend's house if there are indoor pets. Additionally, adolescents are beginning to separate from their families by being away from home with groups of chaperoned youth, but parents of a child with asthma may be reluctant to allow their child the same freedom to travel from home with the potential for asthma exacerbation and the need for emergent intervention. The discovery of self and the formation of one's unique identity may be negatively affected by the presence of a chronic illness.

Chronic illness in children places added stressors on the child and the entire family and often disrupts normal family life. A better understanding of the impact that a chronic illness has on the child and family is needed in order to promote health for these children and an increased sense of normality for their families. Despite the stress of living with a

chronic illness, such as asthma, families can achieve and maintain normalization within the family system.

Asthma: The Most Common Chronic Illness in Children

The overall prevalence of chronic conditions among children is increasing, and asthma remains the most common chronic pediatric illness, affecting more than 7 million United States (U.S.) children (ALA, 2010b; CDC, 2009). Asthma prevalence rates increased 4% from 1980 to 1996 within the pediatric population, but did not exhibit a significant change from 1997-2008 (United States Environmental Protection Agency [USEPA], 2009). Males consistently are more likely to have asthma, with a rate of 7% as compared to a 4% rate among females (USEPA, 2009). There are also a disproportionate number of minority children with asthma: (a) 192 cases per 1000 among African American children, (b) 140 cases per 1000 among American Indian children, (c) 121 cases per 1000 among White children, and (d) 102 cases per 1000 among Asian American children (USEPA, 2009). Therefore, asthma affects the population unequally, and is especially prevalent in African American males (CDC, 2009; USEPA, 2009); therefore it was important to make efforts to include this population in the study sample.

Asthma is a source of stress and a threat to normalization for the child and family for various reasons. The first stressor is the fear of death from the condition. While asthma mortality rates are decreasing, asthma was responsible for 131 pediatric deaths in 2006, which is an adjusted date rate of 0.22 per 100, 000 (ALA, 2010b). The costs associated with asthma care are also a source of stress. The annual health care cost of asthma in the

US is over \$20.7 billion, with \$15.6 billion in direct costs and another \$5.1 billion in indirect costs (ALA, 2010b). For pediatric asthma care in the U.S., \$3.2 billion is spent annually (CDC, 2009). On an individual level, the average cost for an asthma patient is over \$5000 per year, and patients with more severe disease have significantly more cost associated with asthma management (ALA, 2010b). In the current economic climate of uninsured and underinsured children, care for a child's asthma may require significant out-of-pocket costs for a family. Of all hospitalizations for asthma, 44% of these were children (AAF, n.d.). Hospital care is much more expensive than outpatient care and places financial strain on families; asthma ranks third as reasons for hospitalization for children (ALA, 2010b). When a child is hospitalized or at home sick, a parent must be available to care for him/her, which adds financial and time strains on working parents. It is evident that asthma care can stress the family with increased worry for the child's health; it can affect normal family routines, and has serious financial implications from the increased costs of care and decreased work productivity for the parents.

The chronic nature of asthma often is underestimated by the child and family. Asthma is a condition characterized by an ongoing, underlying inflammatory process, with periods of latency and exacerbations (ALA, 2010a). Asthma is the result of a complex interaction of changes at the cellular level leading to chronic inflammation in the airways and hyper-responsiveness of the bronchioles (ALA, 2010a; AAF, n.d.; Banasiak & Bolster, 2008). During the latent phase of asthma, the child is often asymptomatic; however the inflammatory condition remains active, especially in the lower airways. With exposure to a trigger, such as secondhand smoke, the airways

constrict due to hyper-responsiveness, causing coughing and wheezing (ALA, 2010a). The airways in children are very small so a small degree of increased inflammation and/or bronchoconstriction can cause significant respiratory impairment (ALA, 2010a; AAF, n.d.). It is essential for nurses to understand the physiologic processes underlying asthma in order to plan and implement effective care for the asthmatic child and family.

As discussed in chapter one, asthma classification and treatment guides are based on the frequency of symptoms (NHLBI, 2007). Because of small numbers and clusters in certain socioeconomic and ethnic populations, the population of children with severe asthma is often difficult to access for research studies (Guendelman, Meade, Chen, & Benson, 2004; Wu, et al., 2008). However, in a study of children (n= 125) with severe asthma, Jenkins and colleagues (2003) found that the children in the study who had severe asthma were more likely: (a) to be male, (b) to have less severe bronchoconstriction, and (c) to respond better clinically to steroid medication as compared to children with asthma classified as less than severe. While less than 10% of all asthma is categorized as severe asthma, it is important to study this group because of their high mortality rate and frequent hospitalizations.

Asthma management guidelines for children with asthma are specific to the physiology and manifestations of the condition in this population. Specifically, there is significant airway resistance in children due to the following factors: (a) larger tongue, (b) predominantly nose breathing, smaller airways, (c) decreased pharyngeal muscle tone, (d) increased airway compliance, and (e) less elastic recoil (NHLBI, 2007). The respiratory muscles, especially the diaphragmatic muscles, are not as efficient and also

have less endurance in children. Children have fewer alveoli and collateral channels of ventilation, which negatively affects resting respiratory function and is especially significant when compensatory increased respiratory capacity is required, such as during exercise. Children also have high resting metabolic rates and oxygen consumption, resulting in less capacity to adapt to deficits and often leading to an acute asthma attack. Immature neurological breathing control increases the risk of apnea (ALA, 2010a; AAF, n.d.; NHLBI, 2007). These characteristics of lung function in children result in the need for closer monitoring of the child's condition and increase the complexity of the asthma care regimens.

A potential long-term sequela of asthma is airway remodeling, in which structural cellular changes result in permanent changes in the airways that decrease airflow and responsiveness to medication (NHLBI, 2007). Adequate management of asthma is necessary to prevent this long-term complication. Careful management is especially important for children, since they can potentially live with this condition for many decades. However, with the appropriate treatment and support, most children with asthma can have active and healthy childhoods.

Because asthma is the most common chronic illness of childhood, it is important for nurses to understand the disease processes and current treatment guidelines to plan and deliver care for these families. Nurses teach families how to identify the specific triggers for their child's asthma, such as viral infections, allergies, and exercise, and then how to make environmental changes to avoid these triggers. While asthma attacks are often unpredictable and unpreventable, parents can be armed with knowledge and skills to

reduce the environmental triggers and to manage acute attacks. With individualized care based on the classification of the child's asthma and the child's response to treatment, the child and entire family can lead normal lives (NHLBI, 2007).

Applying FMS as a lens to view the family who has a child with asthma provides a framework for the nurse to better understand the impact of asthma on the family's daily routines. When parents and children have adequate information on asthma self-management, they are better able to integrate the necessary treatment into family life, thereby creating a sense of normalcy (Jokinen, 2004; Knafl & Deatrick, 2002). Based on FMS, parents who share the responsibilities related to caring for the child's illness are better able to achieve normalization (Knafl & Deatrick, 2006). Therefore, it is important to include both parents in any asthma education program so that both are able to effectively manage their child's condition in emergent and routine situations. Certain groups are at higher risk for poorer asthma outcomes, such as children from minorities and those who live in urban environments. With this knowledge, nurses can advocate for allocation of resources for these at-risk children and their families to promote normalization. FMSF provides a theoretical foundation for nurses to develop knowledge about the family who has a child with asthma and also to plan and evaluate nursing care that will assist the family to achieve normalization.

Family Management Styles (FMS) as a Theoretical Framework

The Development of FMS

The FMS framework, developed by Knafl and Deatrick (1990, 1996), was utilized as the theoretical framework for the investigation of normalization and FMS in this study (Rodgers & Knafl, 2000). Normalization is a complex concept that has been used in various disciplines. In social services normalization was used as an organizing principle to provide services for mentally handicapped people to offer them normal lives (Rehm & Bradley, 2005). In health care, normalization has been applied as a self-identified descriptor for the child and family and also as a set of strategies to manage care (Knafl, et al., 1996). The current perspective is to utilize the concept of normalization in health-related research as both a cognitive process that is implemented behaviorally through strategies that provide a normal life and as an outcome based on the parents' perceptions (Knafl, et al., 2010; Morse, Wilson, & Penrod, 2000). From this perspective, normalization includes the actions of the family to provide a normal family life and their perceptions of these actions as an outcome (Knafl, et al., 2010). Specifically, normalization is comprised of five defining criteria: (a) acknowledging impairment, (b) defining family life as normal, (c) defining minimal social consequences due to the impairment, (d) participating in behaviors that demonstrate normalcy, and (e) development of a treatment regimen that is consistent with a normalcy lens (Knafl & Deatrick, 1990, 2002; Morse, et al., 2000; Rodgers & Knafl, 2000). After further research by Knafl and colleagues, the five distinct family management styles were identified as: (a) thriving, (b) accommodating, (c) enduring, (d) struggling, and (e)

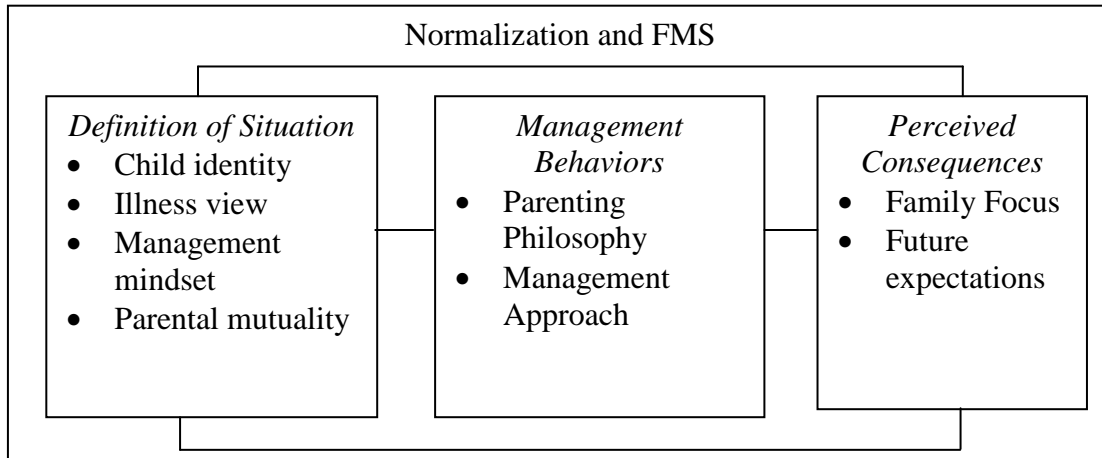
floundering (Knafl, et al., 2008; Rodgers & Knafl, 2000). The FMS framework also includes three interdependent components of normalization: (a) definition of the situation, (b) management behaviors, and (c) perceived consequences of all family members (Deatruck, et al., 2006; Knafl & Deatruck, 2006; Knafl, et al., 2008).

Eight Dimensions of FMS

As the FMS was developed and conceptualized, its three components were further analyzed into eight dimensions that reflect specific aspects of each of the components, as shown in Figure 2. The conceptual component, *definition of the situation*, is comprised by the following dimensions: (a) child identity, (b) illness view, (c) management mindset, and (d) parental mutuality. The second conceptual component, *management behaviors* is comprised of the dimensions of parenting philosophy and management approach. The last conceptual component, *perceived consequences*, is comprised of the dimensions family focus and future expectations (Deatruck, et al., 2006; Knafl & Deatruck, 2003). Each of the eight dimensions is discussed separately below, but they are interdependent parts of the larger components and overall framework.

Figure 2

Eight Dimensions of Normalization and FMS as related to the Three Conceptual Components



Child identity. The first dimension of the *definition of the situation* is child identity, which consists of the parents' views of the child and their abilities (Knafl & Deatrick, 2003). This dimension is analogous to the parents' perceptions of the child's abilities, despite their chronic illness, on a continuum from dependency to normalcy and includes both physical and psychosocial abilities (Knafl & Deatrick, 2003). Researchers have revealed that focusing on the child's capabilities, rather than vulnerability due to a chronic illness, helps to move the entire family toward normalization (Gallo, Hadley, Angst, Knafl, & Smith, 2008; Knafl, et al., 1996; Knafl & Deatrick, 2002; Sullivan-Bolya, Knafl, Deatrick, & Grey, 2003). The positive effect of focusing on the child's normalcy has been studied in different populations, including: (a) families with a child with any chronic illness (Knafl & Deatrick, 2002; Wales, Nadew, & Crisp, 2007), (b) families with a child with cancer (Deatrick, et al., 2006; Neville, 1998; Ogle, 2006;

Simms, 2002), (c) families with a child with type one diabetes (Hollidge, 2001; Mednick, et al., 2007; Sullivan-Bolya, et al., 2003,) and (d) families with a child with a genetic disorder (Gallo, et al., 2008; Knafl, et al., 2010). Only one study was found that focused specifically on the parents' perceptions of their asthmatic children and their abilities to lead normal lives. The parents in the study described that caring for a child with asthma became easier as the child became older because the child was able to participate in the management routine and to communicate their symptoms earlier so care from an emergency department is not necessary (Barton, et al., 2005). Additionally, the parents in the study reported that they were more confident in their abilities to manage their child's asthma after years of experience. In a related study, the researcher utilized constant comparison analysis to identity themes that characterized parents' perceptions of normalization and the parents reported that caring for a child with a genetic condition had become easier and less time consuming since the initial diagnosis (Knafl, et al., 2010). While children with asthma have been included in several of the studies that focused on normalization (Knafl & Deatruck, 2002; Wales, et al., 2007), a gap was noted in the literature that focuses specifically on families who have a child with asthma, the most common chronic illness in children.

Illness view. The next dimension of *definition of the situation* is the illness view, which is based on the parents' understanding and subjective feelings about the child's illness. This dimension includes parents' perspectives of different aspects of the child's illness, including: (a) treatment regimen, (b) cause of the illness, (c) seriousness of the illness, (d) illness predictability, and (d) ultimate course of the illness (Knafl &

Deatrick, 2003). In a qualitative study of families with a child with asthma, Barton and colleagues (2005), determined that parents perceived that the treatment regimen for their child became less burdensome as the child became older, and that the ultimate course of the illness had a positive trajectory as the child aged. When families of children with asthma, diabetes, and epilepsy were compared by Chiou and colleagues (2008), the overall seriousness of the illness and lack of predictability was associated with a higher caregiver burden for those children with diabetes and epilepsy, as compared to children with asthma (Chiou & Hsieh, 2008). Even though the caregiver burden was determined to be less for parents of a child with asthma in, as compared to other illnesses, asthma has an unpredictable nature, and acute attacks often require emergency care and hospitalization because the asthmatic child and/or those with him/her were unable to anticipate and adequately manage the attack (ALA, 2010b). Parents' perceptions of the difficulty in managing their child's illness were important aspects of the illness view component and were also reflected in their management mindset and management approach. When parental focus was on the difficulties caused by the child's illness, rather than the normalcy that can be achieved despite the illness, the family's ability to achieve normalization decreased (Knafl, et al., 1996).

Management mindset. This dimension is also part of the *definition of the situation* conceptual component and reflects the parents' perceptions of the difficulty of administering their child's treatment regimen and the parents' abilities to manage their child's condition effectively (Knafl & Deatrick, 2003). While some chronic illnesses, such as cerebral palsy and diabetes, may require complicated treatment regimens, it is the

parents' beliefs about the regimen that comprise this conceptual aspect of the overall FMS. Therefore, the management mindset is a very subjective experience and is not necessarily disease-dependent. For the child with asthma, the increasing need for independence in disease self-management that occurs in adolescence may be a relief for the parents, as supported by the study by Barton and colleagues (2005). This finding was also supported by authors who studied an increase in self-efficacy in asthma management in adolescent children who attended asthma camp (Buckner, et al., 2007). However, the adolescent's need for independence may also result in increased conflict within the family where there is difficulty allowing the child to take responsibility for his/her asthma management and may also be a source of conflict between parents who do not agree on how to adapt to the child's developmental changes. While a longitudinal measure of overall FMS revealed that length of diagnosis does not have a significant impact on the family's normalization as reflected in FMS (Knafl, et al., 2008), asthma often requires management for a lifetime, and effective patterns that are established as a child are an important foundation for better outcomes as an adult (Smedley, et al., 2003; Wright & Leahey, 2005). Qualitative studies have provided valuable understanding of parents' perceptions of caring for a sick child (Englund, et al., 2001; Gallo, et al., 2008; Wong & Chan, 2006), and now the FaMM developed by Knafl and colleagues (2009) quantifies their perceptions of the management mindset (Knafl, 2009; Knafl & Deatrick, 2006).

Parental mutuality. The final dimension of the *definition of the situation* is parental mutuality which is based on parents' evaluation of their shared beliefs and approaches to

the management of their child's illness (Knafl & Deatrick, 2003). Lack of agreement between parents regarding their child's illness is associated with lower overall FMS scores and less normalization for the family (Knafl, et al., 1996; Knafl & Deatrick, 2006). One of the distinguishing features between the thriving and accommodating FMSs is that one parent assumes the majority of the responsibility for the child's illness management (Knafl, et al., 1996), which is indicative of poor parent mutuality. While researchers who investigated the effect of different parenting styles on adolescent outcomes found that it is more common for parents to have the same parenting style (Simons & Conger, 2007), a gap in the literature was noted regarding the effect of parents' differing beliefs about illness management for their children. Researchers in a study of parents in the neonatal intensive care unit investigated the different attachment behaviors exhibited by mothers and fathers; the mothers reported feelings of shock and surrealism and were not as willing to become involved immediately in the infants' care, as compared to the fathers (Fegran, Helseth, & Fagermoen, 2008). These differences between mothers and fathers may be a barrier to parent mutuality and thereby impede their ability to attain normalization. Additionally, Bem (1993) has described the sexual inequalities within families and the differences in childcare responsibilities based on gender. Exploring and addressing parental mutuality may be a source of stress and disagreement for parents, but enhancing parent mutuality may lead to improved normalization for the family.

Parenting philosophy. The first dimension of the *management behaviors* conceptual component is parenting philosophy. In this FMS dimension, the parents' values, goals and priorities for managing their child's chronic illness are analyzed. Researchers'

findings support that setting goals is important to effective management of a child's illness and promotes positive outcomes (Bursch, Schwankovsky, Gilbert, & Zeiger, 1999; Dokken & Ahmann, 2006; Wright & Leahey, 2005). Specifically, for children with asthma, an asthma action plan is a major component of the current standard of care (ALA, 2010b; Borgmeyer, Jamerson, Gyr, Westhus, & Glynn, 2005). Goals may vary widely among families and are influenced by any of the following factors: (a) religious beliefs (Knafl & Deatrick, 2003), (b) cultural views about health and illness (Akinbami, et al., 2006; Brown, et al., 2005; Lieu, et al., 2004; Shalowitz, Sadowski, Kumar, Weiss, & Shannon, 2007; Smedley, et al., 2003), (c) accessibility of health care (Gupta, Bewtra, Prosser, & Finkelstein, 2006; Javier, Wise, & Mendoza, 2007; Sin, et al., 2003), and (d) past experience with illness (Dokken & Ahmann, 2006; Englund, et al., 2001; Holden, Wade, Mitchell, Ewart, & Islam, 1998; Wright & Leahey, 2005). Setting goals that include providing a normal life for the family may be particularly effective in promoting normalization (Sharkey, 1995). Goals set by the parents are indicative of their underlying philosophy towards management of the child's illness and are integral to achieving normalization.

Management approach. The second dimension of *management behaviors* is management approach, which reflects the parents' assessment of their effectiveness in delivering their child's treatment regimen (Knafl & Deatrick, 2003). The ability to maintain the necessary care for the child on a daily basis plays a vital role in promoting normalcy for the family (Knafl, et al., 1996; Knafl & Deatrick, 2006). It is well established in the nursing literature that teaching families how to adapt a treatment

regimen into their existing lifestyle promotes compliance with the necessary therapeutic interventions (Dokken & Ahmann, 2006; Hanson, et al., 2005; Peterson-Sweeney, 2009). Therefore, the parents' evaluation of how effectively the sick child's treatment regimen is incorporated into normal family activities is central to the family's ability to achieve normalization.

Family focus. The first dimension of the *perceived consequences* conceptual component is family focus, which is the parents' evaluation of the priority placed on the child's illness management within family life. In this dimension, the parents assess the impact of the child's illness on the balance of normal family activities. Based on current research, when a family's normal routine is disrupted due to caring for a sick child, there are potential negative physical and psychological effects for all family members (Boling, 2005; Hayman, et al., 2002; Hobfoll & Spielberger, 1992; Hollidge, 2001; Van Horn & Kautz, 2007). Because an effective asthma treatment plan often includes daily preventative management and planning to anticipate potential triggers, it is important for the family to incorporate the regimen into a normal day without disrupting the family's sense of balance. The child's illness may be perceived as a priority that negatively affects other aspects of family life and is a barrier to normalization.

Future expectations. The last dimension of FMS is future expectations, which is also an element of the conceptual component, *perceived consequences*. This dimension is based on the parents' outlook for themselves and their child and the long-term impact of the child's illness (Knafl & Deatrick, 2003). Some chronic illnesses may have significant negative consequences and complications as the child becomes an adult, such

as in cerebral palsy and type-one diabetes. Although asthma is a serious condition in adults, from the perspective of parents of a child with asthma, it is a reasonable expectation that their child will have a normal lifespan and minimal health issues as they grow into adulthood (Jenkins, et al., 2003; Martinez, 2008; NHLBI, 2007; CDC, 2007). As parents strive to provide a normal life for their child with asthma and other siblings, their worries regarding the sick child's future and their own future may negatively affect the family's normalization (Knafl, et al., 1996; Ogle, 2006).

Each of the eight dimensions represents a unique contribution to the family's FMS and has been explored in the nursing literature. Some of the dimensions are potentially more influential for the family with asthma than others. For example, because of the unpredictable nature of asthma, there is a high probability that the dimension of illness view will negatively affect the family normalization. Conversely, with adequate management in childhood, adult asthma is not considered a major impediment to living a healthy life; therefore future expectations are probably not a major concern for parents of a child with asthma. However, because FMS is based on a parent's perception of their child's illness, there may be great variance within and between dimensions.

FMS Framework in Nursing Research

In this section, the empirical support for application of the FMS framework is evaluated in several studies (Deatrick, et al., 2006; Hines & Krowchuk, 2010; Knafl, et al., 1996; Knafl & Deatrick, 1990; Morse, et al., 2000; Peck & Lillibridge, 2005; Rehm & Bradley, 2005; Sharkey, 1995). These studies were chosen for evaluation for several reasons. First, there was representation from both quantitative and qualitative studies,

which demonstrates the diverse applicability of FMS. Next, the review included foundational studies, such as the initial conceptual analysis of normalization. As the theory developed from the initial qualitative studies, the authors developed the FaMM tool and applied this measure to quantitative inquiry of FMS. An interventional study was also included as an exemplar of the use of the theoretical framework in the clinical setting. The study of maternal perceptions was especially relevant to the study of maternal and paternal evaluations of family FMS.

In the first study, researchers support the use of FMS as a theoretical framework in a qualitative study of four families using grounded theory approach and secondary analysis of data from a larger study (Sharkey, 1995). The population sample was comprised of families receiving home care services for a chronically ill child. Parents participated in semi-structured interviews that were analyzed for themes. Uncertainty was an evolving experience that began with the diagnosis of the child's condition and changed based on the parents' knowledge of disease management (Sharkey, 1995). Uncertainty threatened the family's previous ways of functioning and was a pervasive concern for the family's future. The theme of normalization emerged as an attempt to decrease uncertainty within the family and to maintain familiar routines despite the child's care requirements. By achieving normalization within the family, the negative impact of long-term uncertainty was lessened (Sharkey, 1995). In this study, there was an inverse relationship between the two concepts of uncertainty and normalization that were identified by these families with chronically ill children. Consistent with a grounded theory approach, the authors

did not specify a foundational conceptual model, but the findings relate to the future development of normalization and FMS.

In 1990, Knafl and Deatrick performed a qualitative descriptive study with illustrative quotes from two families from a larger study with the purpose of conceptualizing FMS. From this study, the authors clarified the three components of FMS as: (a) situation, (b) management behaviors, and (c) sociocultural context (Knafl & Deatrick, 1990). The authors also determined that the FMS model does not have a specific definition of family and can therefore be applied to a wide range of pairs/groups that consider themselves as family (Knafl & Deatrick, 1990).

The next study was a mixed methods longitudinal study using open-ended interview questions, in addition to quantitative surveys, to investigate how families respond to childhood chronic illness (Knafl, et al., 1996). In this study, the characteristics of families with each family management style were identified and described in detail (Table 1) (Knafl, et al., 1996). In addition to further defining each FMS, the investigators interviewed these families at a 12-month follow up to determine the stability of FMS over time. This follow-up revealed that FMS was relatively stable and *thriving* and *floundering*, the anchors of the continuum were the most stable. For families who changed FMS category during the 12 months, it was likely to be in a negative direction and usually moved only one category (Knafl, et al., 1996). There was no association between FMS and the specific disease, FMS and length of diagnosis, or length of diagnosis and stability of FMS (Knafl, et al., 1996), so planning interventions aimed at a

certain FMS based on diagnosis or length of illness was not supported by the researchers in this study.

Table 1

Characteristics of Families for each Family Management Style Category

Category	Characteristics
Thriving	Confident. Proactive. Illness in background. Both parents involved and see positive consequences.
Accommodating	Both parents are confident in care abilities, but mother is primary caregiver. Family is anxious about future.
Enduring	Care is burdensome and requires much effort. Child is viewed as a tragic figure that needs sheltering. Illness has major negative consequences.
Struggling	Parental conflict regarding child's disease management. Fear health-related complications for child. Illness is in foreground. Pervasive sense of negativity.
Floundering	Lack of parenting philosophy. No adherence to treatment regimen. Sense of inadequacy and hopelessness.

The next study was a comprehensive review of research and theoretical literature related to the concept of normalization and explained how the attributes of normalization were initially identified and then revised (Deatrick, et al., 1999). The authors clarified the concept of normalization for its use as a conceptual framework in research. This type of scholarly inquiry is integral to advancing the science and strengthening the foundation of nursing research and theory. In 2002, Knafl and Deatrick continued their investigation of normalization for families with a child with chronic illness in another qualitative study of 59 families, who participated in two interactive interviews, conducted 12 months apart.

This study utilized family case examples to identify attributes of normalization and considered the various ways normalization was manifested in families (Knafl & Deatrick, 2002). Barriers to normalization were also identified, along with the realization that normalization was not the goal in some situations and has a cultural component (Knafl & Deatrick, 2002).

Case studies were used to study the clinical application of FMS to families of children with cancer by Ogle (2006). The investigator compared the case studies of a family with a *thriving* FMS with a family with a *floundering* FMS as they dealt with a child's cancer treatments (Ogle, 2006). By choosing the FMS at each end of the spectrum, the author was able to elucidate the differences in the families' experiences with an ill child. Normalcy emerged as a theme from the family with a *thriving* FMS, whereas the family with a *floundering* FMS had themes of uncertainty and conflict. Again, uncertainty and normalcy were identified as opposing themes in families who have an ill child (Ogle, 2006; Sharkey, 1995).

Sullivan-Bolya and colleagues (2003) utilized the FMS framework in a qualitative study of maternal management behaviors of children with type-one diabetes. According to the theoretical framework, there are five specific aspects of management behaviors, which are: (a) goals that drive the behavior, (b) underlying definitions of the necessary behaviors, (c) measureable actions the family must manage daily, (d) implementer(s) of the behavior, and (e) foci of the behavior (Knafl, et al., 1996). In the study, mothers' reports of management behaviors were categorized as: (a) strict adherence, (b) flexible adherence, and (c) selective adherence. The researchers determined that the mothers

moved through various phases to obtain the knowledge and skills to adequately manage their child's chronic condition.

The concept of normalization was investigated by Rehm and colleagues (2005) in families who had a medically fragile/technology dependent and developmentally delayed child. In this qualitative study, the researchers identified that normalization involves focusing on how one's family is more similar to, rather than different from, other families. For the families in this study who were dealing with complex daily care regimens, their daily lives did not fit established attributes of normalization, but they were able to recognize normal and positive aspects of their lives, while acknowledging their daily challenges related to caring for their child (Rehm & Bradley, 2005). The researchers highlighted an important aspect of normalization; there are situations in which normalization may not be necessary or even desirable. Families in the study concluded that they were able to have a good life without achieving normalization, based on established measures.

Morse and colleagues (2000) conducted a study with mothers of disabled children and studied normalization in these parents of chronically ill children. Normalizing behavior was defined as: "any behavior where the child sought to identify with another individual or group" (Morse, et al., 2000, p. 662). The children were observed during daily activities, and the mothers were interviewed about their daily care experiences. Normalizing behaviors of the children toward a reference groups were identified as: seeking commonalities with others, developing their own abilities, and maximizing capabilities. Mothers in this study often manipulated factors to help their children fit in

either the disabled or normal environment, depending on the circumstances. Mothers reported that over time they were able to incorporate their child's special needs into the family's daily routine, thereby mixing the disabled and normal aspects of their child's life and achieving normalization.

In a different patient population, FMSF was presented as a useful tool for assessing the complex needs of families who have a child with a brain tumor (Deatrick, et al., 2006). Specific behaviors that parents may exhibit in each of the eight dimensions of FMSs were outlined, so nurses were able to recognize families who were having difficulty with normalization. The researchers recommended that categorizing the families into one of the five FMS is a useful assessment tool to identify families who require interventions to promote normalization among families who have a child with a brain tumor.

Lastly, Gallo and colleagues (2008) performed a qualitative study of 142 parents and caregivers from 86 families who were part of a larger qualitative study of families with chronically ill children, including various illnesses. While the authors did not explicate a specific conceptual framework, the data are from a larger study on normalization and FMS (Gallo, et al., 2008). In this study, over half of the parents/caregivers had concerns about health insurance and the child's school performance, which implies that families' concerns transcend direct care for their child and may impact normalization within the family.

As stated earlier, normalization is both a process and an outcome, and both of these aspects of the concept were studied by Knafl and colleagues in 2010. In this study, the

normalization was analyzed as an outcome using constant comparison analysis, and families were designated as Normalization Present (NP) or Normalization Absent (NA). Parents' perceptions of condition management, parenting role and condition impact were also analyzed for themes as the process of normalization was studied (Knafl, et al., 2010). In this secondary analysis, the meaning of normalization for parents of a child with a chronic genetic condition was analyzed, and patterns were identified for normalization, as a process and an outcome. Balancing condition management with normal life was identified as an important strategy for achieving normalization.

Even though most of the research applying FMS has been qualitative, the FMS theoretical framework was an appropriate lens for a quantitative study. The quantitative tool, the Family Management Measure (FaMM), was developed to measure family normalization and preliminary reliability and validity data are strong (Knafl, 2009). Qualitative studies often serve as the foundation for theory development (Meleis, 2007; Munhall, 2007), which is then used as the basis for follow-up quantitative inquiry. The qualitative perspective allows exploration of a phenomenon when there is a paucity of knowledge about the subject and more information is needed to develop instruments to measure variables using a quantitative approach. The qualitative groundwork has been laid in the area of how families respond to having a chronically ill child, and instruments, such as the FaMM, are available for application in this area of inquiry.

Strengths and Limitations of FMS as a Theoretical Framework

This theoretical perspective provides a lens for examining the phenomenon of childhood asthma from several different aspects. First, it was a strength that this theory

can be used to describe the problem of interest and better understand the family's individual experience with their child with asthma based on their specific FMS. Next, the FMS theory can be used for planning interventions that are individualized for the family, based on their identified FMS. Another strength was that FMS can be used to evaluate interventions by the family's movement toward normalization and a more adaptive FMS. As nurse scientists work to build a body of knowledge that is based in the nursing discipline, it is important to use nursing theories, such as FMS, as theoretical foundations for research studies (Meleis, 2007). FMS is also appropriate for use with qualitative and quantitative research methodologies. An example is framing the qualitative research question to investigate Knafl and Deatrick's (1986) concept of normalization by asking the question, "How has your child's asthma treatment regimen affected your family's lifestyle?". The FaMM (Knafl, 2009), quantifies the concepts of the theoretical model in order to facilitate the measurement of the theoretical components. An additional strength was that the theory addresses barriers to normalization. Lastly, the FMS theory also views childhood asthma as a dynamic phenomenon which is consistent with asthma evaluation and treatment (NHLBI, 2007).

A major concern with the application of the FMS theory was that individualization would be lost by placing families into categories and ascribing the category's characteristics to all families who have a child with asthma. This theoretical perspective lacked the inclusion of the potential consequences of normalization, which are not always desired or positive (Deatrick, et al., 1999; Morse, et al., 2000). There are lifestyle and environmental changes that significantly improve asthma outcomes, such as reducing

exposure to the following known asthma triggers: exercise, indoor pets, cold temperatures, dust mites, and emotional stress (ALA, 2010b; Morawska, et al., 2008). If parents ignore the recommendations for modifying these environmental factors in an attempt to promote normalization for their child and family, the child's asthma management will suffer. Barriers to normalization have not been adequately addressed by the theoretical framework to date.

Factors that Impact Asthma Management

Risk Factors

Dealing with a chronic illness on a daily basis presents different challenges for families, as compared to having a child with a self-limiting condition. While each family has an individualized response to their child's chronic illness, the following risk factors were investigated as they relate to families with a child with asthma. Based on the theoretical framework for this study, risk factors were defined as any factors that had a potentially negative impact on normalization and the FMS and inhibited the parents' efforts to provide a normal family life for all family members. It was important to investigate these factors to determine their influence on normalization as reflected in FMS.

Child's gender. From a broad perspective, there were differences in how parents responded to a sick child that are based on perspective. Globally, parents in India were more likely to use less expensive public health care and to neglect neonatal care for a female child as compared to male children (Willis, et al., 2009). However, in Pakistan,

researchers did not find differential care seeking based on gender despite differences in mortality rates between boys and girls (25 more deaths per 1000 births as compared to boys) (Nuruddin, Hadden, Petersen, & Lim, 2009). While these gender-based differences in health-related decision making were not evident in the U.S., parents may react to a child's illness with a gender specific response. For example, in a study of children with diabetes, parents reported that boys were less self-reliant in managing their diabetes; whereas parents of girls did not report their children as lacking self-reliance (Mansfield, Addis, Laffel, & Anderson, 2004). Similarly, in a study of children with asthma mothers were frequently identified as *alert assistants* for their male children and were involved in managing their child's illness, so it would have less impact on normal activities, but this role was not as prevalent among mothers of female children with asthma (Iley, 2007). Because parenting and socialization of children often varies based on gender (Bem, 1993; Garbarino, 2006), it is prudent to investigate how the impact of a child's chronic illness varies based on child's gender.

There are disparities between the genders in asthma prevalence. Males are more likely to have asthma, with a rate of 15% among males, as compared to a 11% rate among females (ALA, 2007; CDC, 2009). Therefore, is important to study the impact of the child's gender on the family management style. Knafl and colleagues (1996) included gender as a variable in the qualitative study that provided the foundation for the five FMS's that were measured in the study using the Family Management Measure (FaMM). In Knafl's study, there was a relative balance of boys and girls in the FMS's that reflected normalization (thriving and accommodating) and those FMS's that reflected

difficulties normalizing family life (enduring, struggling, and floundering), due to the care demands of a sick child (Knafl, et al., 1996). Because asthma affects males more often than females, it was important to investigate if having a male child with asthma has a different effect on the family's normalization, as compared to a female child. A gap in the literature was noted related to studies that focus on gender differences between male and female children and how their chronic illness impacts the family; therefore, this study investigated the effect of child's gender on family FMS.

A male child with asthma may experience increased disruption to the family's expectations, as compared to a female child. For example, exercise-induced asthma may prevent the school-age or adolescent boy from participating in some sports. This inability to play sports with other boys may result in the child feeling self-conscious and different from his friends. From the family's perspective, the parents may be disappointed that their son cannot participate in sports; this may lead to problems within the family system and relationships. If the child feels he does not meet his parent's expectations, he may feel guilty and inadequate as a son. With the evolving loss of strict gender specificity in societal roles and sports, these same expectations of excelling in certain sports may also apply to girls with asthma (Bem, 1993).

From a social perspective, boys are less likely than girls to accept asthma as a part of their personal identity (Iley, 2007), and thus may have more difficulty incorporating necessary asthma management into daily routines and treating themselves in public settings. However, because boys often minimize the effect of asthma, they may be more likely to participate in physical activities, especially sports, and therefore experience

higher levels of normalization as compared to girls (Iley, 2007). Even though media has brought attention to athletes who have excelled despite having asthma, many parents continue to view asthma as a condition that limits physical activity for their children. Asthma camps are innovative interventions that allow children with asthma to safely participate in activities that may otherwise be discouraged for them (Buckner, et al., 2007). Additionally, asthma camps are effective in increasing self-efficacy among the children and their ability to manage asthma, along with helping to decrease the stigma of having a chronic illness by creating support among children with asthma (Barrera, Chung, & Fleming, 2004; Buckner, et al., 2007). Furthermore, while boys report being more fearful of the stigma of having a chronic illness and tend to hide it from peers, there is no clear conclusion if the social stigma of having a chronic illness differs between genders (Iley, 2007). This was another important gap in the literature, because the child's response to the stigma of asthma may affect normalization for the family.

Child's race. According to the CDC, minorities and children living in urban areas have higher morbidity and mortality due to asthma (CDC, 2009). Fortunately, asthma rarely leads to death in children, and only 141 (< 5%) of the asthma deaths were children under the age of 15 (ALA, 2010b). In the third National Health and Nutrition Examination (NHANES) Survey, African American children aged 10 years and younger had the highest risk of increased asthma prevalence, morbidity, and mortality (CDC, 2009), which was compelling evidence that this population should be targeted for intensive interventions to promote coping and adaptation. Miller's (2000) study provides support for increased focus on this population. In Miller's findings, White

children with asthma benefited from increased family income with decreased asthma prevalence; however, African American children with asthma did not experience this same effect of improved asthma rates and care with increasing income (Miller, 2000). In this study sample, the differences in asthma outcomes and health care were related to race as a risk factor, rather than income and other societal factors.

In a study of racial variation among parents' perceptions of having a child with asthma, the following variables were measured: (a) expectations for the child's functioning with asthma, (b) concerns about medications, (c) interactions with health care providers, and (d) competing family priorities (Wu, et al., 2008). The researchers discovered that parents of African American children had lower expectations for their children's functioning ($p < 0.001$), higher levels of worry about their child's asthma ($p < 0.001$), and more competing family priorities ($p < 0.004$), as compared to parents of White children (Wu, et al., 2008). These investigators implied that parental expectations may differ between races, and ethnic/racial differences should be addressed, in order to decrease disparities in asthma outcomes.

Another variable in disparate asthma outcomes was exposure to poor air quality as an environmental asthma trigger, and African Americans are more likely to live in urban areas that have poorer air quality (ALA, 2010b; CDC, 2009). There was a disproportionate burden of exposure to air toxins in the African American population. Specifically, 68% of African Americans live within 30 miles of a coal-fired power plant, as compared to 56% of Whites. Also, ozone exposure increases the mortality rates among African Americans at a higher rate than for Whites. Lastly, researchers found

indoor particulate matter levels were higher than outside levels in an urban Maryland study (ALA, 2010b). Laws that restrict air pollution will help prevent acute asthma attacks in sensitive children and may result in better asthma outcomes.

Reluctance to seek care from health providers due to mistrust is a cultural characteristic prevalent among minority groups, especially African Americans that may contribute to poorer asthma outcomes and family management problems (LaVeist, 2002; Smedley, et al., 2003). Health care providers need to be aware of these cultural beliefs and approach asthma care for minority children with interventions that are culturally competent and apply principles of cultural leverage (Chin, Walters, Cook, & Huang, 2007; Fisher, et al., 2007). Families from minority groups often are economically disadvantaged and bear an enormous financial burden caring for a child with asthma. In 2008, the median household income for African American families was \$ 34,218 as compared to \$52,312 for White families, and 24.7% of African American families lived below the poverty level, as compared to 8.76% of White families (The United States Census Bureau, 2008). Therefore, poverty may contribute to additional stressor for these families and may impair their ability to maintain a normal family life.

Child's age. There was contradictory information in the literature related to the effect of a child's age on the family's ability to normalize. According to Knafl and colleagues (1990, 1999), normalization is the family's ability to maintain a normal family life, and the definition of normal is determined by each individual family and may vary greatly. In several studies, families reported that the stress and demands of the management of a child's chronic illness decreased as the child became older, but this

effect was disease-dependent and not generalizable to all chronic illnesses (Barton, et al., 2005; Hopia, et al., 2004; Peck & Lillibridge, 2005; Wales, et al., 2007). Based on developmental considerations, a nurse would expect that caring for a younger child with a chronic illness imposes more of a disruption to normal family life, than an older child who can participate more in the self-management of the condition (Dokken & Ahmann, 2006; Wright & Leahey, 2005). Specifically, researchers in a nested qualitative study of Australian families with children with asthma investigated the effect of the child's age on the parents' caregiver burden. In this study, the parents reported that "it gets easier" as the child ages and is developmentally able to assume more responsibility in their self-care (Barton, et al., 2005). In a study of fathers of medically fragile children, fathers reported that they used a variety of coping mechanisms over time to cope with the daily stress of their child's condition, and that over time they were able to accept their child's illness as part of daily life (Peck & Lillibridge, 2005). From these findings, it can be inferred that caring for a chronically ill child becomes less burdensome as the child becomes older. As expected, asthma may be less of a burden for parents of older children and is subsequently less likely to cause stress for all family members. In a study of children with various chronic illnesses, Knafl and colleagues (1996) did not find a difference in the children's ages between the FMS's that reflect normalization and those FMS's that reflect poorer family normalization, which may indicate that age may not be an influence on family normalization.

Conversely, in a study that focused on family household routines as a factor that promotes positive outcomes for a child with asthma, the families with a school age child

or younger were more likely to have a greater degree of household routines and less family burden from caring for the child (Peterson-Sweeney, 2009). As the child grows older, the family may have less influence in the child's decision-making, as the peer group becomes more important (Erikson, 1950), and asthma management may be less consistent. Parental lack of control may be a source of stress for parents and may be reflected in difficulty allowing the child appropriate freedom and responsibility for their developmental age (Barton, et al., 2005).

Hopia and colleagues (2004) investigated nursing interventions that promote health for families of children with chronic conditions when the children were hospitalized. While the nurses individualized the interventions based on the child's age, the study did not include an evaluation of the impact of the chronic condition as related to the child's age. In addition, Wales and colleagues (2007) focused on the parents' and children's views on managing their chronic condition and included children with diabetes (n=14) and children with asthma (n=6). Data were analyzed using a thematic approach and the following issues related to a school-age child assuming more responsibility for self-management were identified: (a) change in family dynamics, (b) parents relinquishing control, (c) potential for conflict when one parent has been in control of the child's condition, (d) the importance of the child's knowledge of their condition (Wales, et al., 2007). Researchers concluded that the transfer of responsibility to the child for self-management did not occur in a linear fashion and involves movement toward more independence, coupled with periods of regression to dependence on the parents.

Lastly, in a study that implemented a home visiting asthma education program for caregivers of children less than seven years old, researchers found that the number of medical visits for acute asthma was moderately correlated with the child's age ($r = -0.32$); therefore, older children with asthma in this study had fewer medical visits compared to younger children (Brown, et al., 2005). Additionally, a linear relationship between a child's age and a decreasing impact on the family system was not discovered in the review of current literature. Because of the conflicting evidence related to the impact of the child's age on family normalization, it was essential to include this variable in the study.

Asthma severity. The reactions of parents of children who are diagnosed with an eminently life-threatening condition, such as cancer, have been studied, and certain coping stages, including shock, uncertainty, establishing meaning, confrontation, and establishing a new perspective have been identified (Mishel, 1983; Neville, 1998; Wong & Chan, 2006). Parental stress was measured using the Parenting Stress Index in a study of parents of children with congenital heart disease (Morelius, Lundh, & Nelson, 2002). In this study, parents of children with a less serious heart condition had an equivalent degree of stress, as compared to parents whose children had more serious conditions. Researchers discovered that severity of a child's illness was not a significant factor in overall stress for parents in the study sample. However, because asthma often causes uncertainty, with unexpected exacerbations that are potentially life-threatening, it was impossible to ascribe a linear coping trajectory. In a 2003 study of children with severe asthma, the authors described the characteristics of children with severe asthma as: (a)

male, (b) with less bronchoconstriction as compared to adults with severe asthma, and (c) having positive clinical outcomes after steroid treatment, when compared to children with asthma not categorized as severe (Jenkins, et al., 2003). Specifically, no studies were found that investigated the severity of a child's asthma as a predictive factor of stress for the entire family.

Protective Factors

For this study, protective factors were defined as any factor that may promote normalization for the family that has a child with asthma. These factors were viewed as protective to the family's ability to maintain normalcy in their family management, despite having a sick child. While normalcy was defined differently by each parent dyad's interpretation for their individual family, it was measured quantitatively by the instruments used in the study. A review of the current literature for the protective factors for the study follows.

Child's participation in an asthma education program. Self-management is an important coping mechanism for both the child and their family. When the child and family have the adequate information and skills to successfully manage the illness, they are empowered and feel less stressed and overwhelmed (Bandura, 1997; Buckner, et al., 2007; Robinson, et al., 2008; Zebracki & Drotar, 2004). Asthma education programs have been implemented in partnerships with school systems to provide information to children with asthma about how to better manage their condition. In general, these programs have been successful in providing asthma education in the school setting but have encountered difficulties in outcome measurement as shown in the following studies.

A comprehensive school-based asthma program that was implemented in 54 elementary schools with 13, 247 students from a urban setting, utilized three separate educational programs and medical management for the children with asthma (Gerald, et al., 2006). Participants in the study exhibited a significant increase in asthma knowledge; but despite intensive intervention over 3 years, morbidity measures (school absences, grades, emergency room visits, and hospitalizations) did not change. Researchers identified that it was difficult to maintain the fidelity of the asthma education programs due to the following factors: (a) students changed schools often with transfer of records, (b) high faculty and staff turnover at the schools necessitated repeated training, (c) excessive demand on school staff, and (d) cost of supervising trained volunteers. Because this study was conducted with inner-city, low-income, minority children who do not utilize health care resources, the results are not generalizable to other populations, but it was evident that increased knowledge about asthma did translate into better asthma management and/or outcomes for these school-aged children.

Another large scale school asthma education program (n=1730) partnered with 70 elementary schools to provide a comprehensive asthma intervention to promote self-management for children with asthma (Bartholomew, et al., 2006). First, schools collaborated with parents and clinicians to develop an asthma action plan for each child. Next, the program implemented computer-assisted education that was individualized for the child's asthma symptoms. Lastly, a school environmental assessment and intervention was planned (Bartholomew, et al., 2006). Children who received the intervention had improved school performance and fewer absences than children in the

comparison group, and the program was determined to be effective in promoting asthma self-management among children but did not affect their health status as measured by frequency of episodes and symptoms. Again, an asthma education program had positive outcomes but was not effective in changing measured physiologic outcomes.

Anderson and colleagues (2005) performed a longitudinal evaluation of the comprehensive, public-school based intervention, *Open Airways for Schools*, and included surveys of principals, teachers, parents, children with asthma, and healthy children. While parents were not included in the intervention, they were included in the follow-up study, because the researchers were interested in any impact that the program had on the parents' voiced concerns about their child's safety in the school setting if an asthma attack occurred. The researchers concluded that after participating in an asthma education program, school staff were not knowledgeable about how to manage asthma in the school setting, and most schools did not have an on-site school nurse. When teachers were asked to list three steps to take if a child were experiencing an acute asthma attack, 39% of the respondents gave at least one inappropriate step, such as *encourage the child to bend over* and *encourage the child to breathe into a paper bag*, which was concerning to the researchers (Anderson, et al., 2005). Lack of knowledge would also be a source of concern for parents who assume that there are people in the school setting who can manage their child's asthma until emergency medical care arrives. Knowledge levels of children without asthma did increase after the educational intervention, but they continued to have misconceptions about how to manage an acute attack. Children with asthma reported feeling embarrassed about their condition and worried about being able

to participate in physical activities and the negative impact on their school performance, even after the asthma education program. Overall, knowledge about asthma was increased among all categories of participants after the intervention and the need for school nursing services was identified (Anderson, et al., 2005). From these study results, one can conclude that a child who has participated in a school-based asthma education program is more likely to have sufficient information about self-management of asthma but may still have concerns about the negative impact of asthma in the school setting.

Shaw and colleagues (2005) implemented a classroom-based education curriculum, *First Aid for Asthma*, a 9-module instructional program in asthma self-management that included healthy children, in addition to children with asthma. In addition to measuring asthma knowledge, the researchers measured: (a) asthma attitudes, (b) self-efficacy, (c) asthma self-management, and (d) quality of life in the adolescents after the intervention. Mean scores of asthma knowledge and self-efficacy increased significantly for the participants who had asthma (Shaw et al., 2005). Most students had positive attitudes toward asthma before the intervention, which may have created a ceiling effect, because these attitudes decreased slightly after the intervention. This decrease may have been due to a better understanding of the seriousness of asthma and its potential implications. Knowledge about asthma increased among both groups of children, and self-efficacy increased among the students with asthma. These study results have important implications, because attitudes about asthma management are components of the FMS, and children who have participated in similar programs may have improved attitudes

about self-management of their asthma that translates into less caregiver burden for parents.

In the last study in this review, the authors included a literacy intervention into an asthma education for underserved children in an urban setting (Robinson, et al., 2008). It was proposed that the literacy enhancement was an important factor in improving self-efficacy in the children, which would positively impact their asthma related-outcomes. All children in the program had significant improvement in both their reading and self-efficacy levels after the intervention. In addition, multivariable logistic regression demonstrated that increased self-efficacy was directly related to decreased hospitalization and emergency department visits, which were used as asthma outcome measurements for the study.

Because participation in an asthma education program has been associated with improved outcomes of various types, including: (a) increased school attendance, (b) better school performance, (c) enhanced self-efficacy levels, (d) fewer hospitalizations and emergency department visits, and (e) quality of life for the child who has asthma, it was included as a variable in the study. If the child with asthma had participated in a formal school-based asthma education program, there may be a positive impact on the child's asthma management that may promote normalization within the child's family.

Parent's participation in an asthma education program. Children who lack access to prompt, quality treatment for acute asthma exacerbations are at increased risk for poorer short-term and long-term health outcomes (Gupta, et al., 2006). Parents' lack of knowledge about effective management of illnesses at home and when to seek

emergent care is often related to inadequate usage of primary health care and the subsequent over usage of episodic, expensive emergent care (Borgmeyer, et al., 2005; Brown, et al., 2005; Clayton, 2005; Gupta, et al., 2006). Parenting classes and education for parents of children with chronic illness are effective methods of increasing parents' abilities to appropriately manage acute exacerbations of asthma as a chronic illness at home and proper use of emergent care (Brown, et al., 2005; Gupta, et al., 2006; Levy, et al., 2006); however, a review of the literature revealed a paucity of asthma education programs that either include parents or are targeted to parents of children with asthma.

When a child is first diagnosed with asthma, the parents often have a strong emotional response and need time to accept the implications of the child's illness for both the child and family. A qualitative study by Maltby and colleagues (2003) investigated the phases parents progress through to develop competence in caring for their child after receiving a diagnosis of asthma. After the initial emotional reaction, which was described as *naming asthma*, the parents moved into a phase of *taking on reality*. It was in this second phase that the researchers identified the theme of wanting information about asthma, in order to provide the necessary care for their child (Maltby, et al., 2003). In the third phase of *getting on with it*, the parents integrated having a child with asthma into the parenting role and normalized the child's treatment regimen into family life. The parent was able to treat the sick child like other children in the family, while being aware of health issues, which is an essential component of normalization (Knafl & Deatrick, 2002; Knafl, et al., 2008). In the 2003 study, parents' initial feelings of grief and fatigue were replaced with a sense of competence in their ability to manage their child's asthma

(Maltby, et al., 2003). Based on parents' reported needs in this study, asthma education programs for parents may be an integral aspect of promoting normalization for families with a child with asthma.

Although school-based programs usually have a primary focus on children with asthma, there are programs that are either aimed toward parents, or include parents in programs, along with the school children. An example of a comprehensive school-community initiative that included parents was the *Healthy Learner Asthma Initiative* that translated national asthma guidelines into an asthma education program in the school setting (Erickson, Splett, Mullett, Jensen, & Belseth, 2006). This program also introduced the role of the asthma resource nurse, who was described as: (a) an expert in asthma management, (b) an advocate for evidence-based care, and (c) a change agent for better asthma outcomes in school settings (Erickson, et al., 2006). This program had many strengths, including: (a) utilizing evidence-based guidelines, (b) creating the position of a chronic disease resource nurse, (c) partnering with parents and providing education for parents, and (d) partnering with health care providers to provide medical care. While the program did not provide direct education to the parents, the inclusion of parents in this education program was innovative and was accomplished by using a variety of methods, including: (a) focus groups, (b) phone calls, (c) handouts, and (d) culturally-specific community-based asthma education programs. Evaluation of the program indicated fewer asthma visits to the school health office, improved school attendance among students who attended the educational program and a foundation for collaboration between the school and health care systems (Erickson, et al., 2006).

A home visiting intervention was implemented in a low-income, urban, primarily African American neighborhood as part of the *Wee Wheezers at Home* asthma education program that targeted children less than seven years old and included the primary caregiver, usually the mother, in the program (Brown, et al., 2005). Researchers asked the caregiver to quantify asthma as a problem for the family, when compared to other problems the family faced. Caregivers responded as follows: (a) 35% rated asthma as a small problem, (b) 33% rated asthma as a medium problem, and (c) 33% rated asthma as a big problem for the family. The average age of the children in this study was 4.3 years old, with a range of 1.3 to 6.9 years. Caregivers received a 90-minute educational lesson for 8 weeks; the home visitors were encouraged to include the child and others in the home in the educational sessions. Written information was given to the family after each session, and homework was assigned periodically to the participants. Completion rate of the entire 8-week session was 71%, which was higher than reported completion rates for clinic-based and school-based education programs for low-income families. However, scheduling and maintaining appointments were significant problems and resulted in the mean interval of 1.9 weeks rather than 1 week (Brown, et al., 2005). When researchers evaluated the effectiveness of the program based on attainment of learning objectives for each module and based on these criteria, there was a significant increase in caregiver knowledge of asthma management after the educational intervention.

Despite the preponderance of study results that are supportive of the positive effects of parent education, parents may be recalcitrant to seek information, fearing that it may cause them more stress and disruption to their daily lives. Researchers in rural Australia,

who explored the phenomenon of normalization among fathers of chronically-ill children, found that the fathers minimized knowledge-seeking behaviors as a strategy to normalizing their daily lives (Peck & Lillibridge, 2005). In this study, the fathers appeared to be threatened by new information and contended that understanding came from experience, rather than patient and family education. Based on these study findings, nurses must be aware that information may be accepted from others who share a common experience, rather than health care providers.

There were few studies described in the literature that include parents in asthma education programs so it was difficult to accurately determine the impact of this variable on the children with asthma and their families. Because the family is the focus of pediatric care, it was important to ascertain the impact of educating parents about their child's asthma on family normalization.

Past and current parental experience with asthma. The effect of parental experience with asthma may be either protective or harmful in the current family situation. It is well established that the family of origin serves as a learning environment for socialization to certain roles and expectations, which include the management of illness (Coffey, 2006; Kratz, et al., 2009; Sharkey, 1995). Certain perceptions and expectations may be established when a person has an illness as a child, and these perspectives may range from negative to positive, depending on the individual's experiences (Colliver, 2007; Wright & Leahey, 2005).

The parent of a child with asthma may have also been a child with asthma, which may influence how he/she parents their own child with asthma. The parent's response to

growing up with a chronic illness has a potentially wide range of effects that may be positive or negative. If the parent focused on the negative aspects of growing up with asthma, it is logical to conclude that the parent may transfer the negative attributes of asthma into the current situation with the child and be more overprotective with the sick child (Carpentier, Mullins, Wolfe-Christensen, & Chaney, 2008). However, if the parent experienced developmentally appropriate independence with self-management of asthma and was not limited in participating in important activities, it is reasonable to conclude that the parent may have a sense of confidence in managing asthma and may transfer this to their child with asthma (Kratz, et al., 2009; Wright & Leahey, 2005). Parents who had asthma as a child should be included in asthma education programs, because the recommended medical treatment for asthma has changed significantly within the last few years, and parents often are insecure about their abilities to competently care for their chronically ill child (Frain, et al., 2007; Hoff, et al., 2005).

A parent who had and/or currently has asthma and is parenting a child with asthma may experience either a positive or negative impact on their ability to normalize the current family situation. If the parent focused on their competence to care for their own illness and also feels competent to care for their child's asthma, normalization will be facilitated (Chiou & Hsieh, 2008; Svavarsdottir, et al., 2005); Realistically, the parent may be at an increased risk for experiencing stress from the management of their own illness, in addition to their child's asthma, and may be less likely to be able to provide a normal family life (Abern, Ark, & Byers, 2008; Mednick, et al., 2007). In a 2009 study, mothers with a chronic illness were compared to healthy mothers, and the researchers

found that fatigue was a significant predictor of parenting difficulties for mothers with rheumatoid arthritis and healthy mothers, but not for mothers with multiple sclerosis (White, et al., 2009). Psychological illness in a parent also affects the family's normalization. In 2008, Davis and colleagues studied the effect of depression on proxy reported health-related quality of life (HRQOL), and maternal depression was negatively correlated with maternal reports of HRQOL in their children (Davis, Davies, Waters, & Priest, 2008). While it is logical that ill parents will have more difficulty providing a normal family environment, there were few studies that investigate this phenomenon. For this study, parents were asked if they had asthma as a child or currently have asthma, to examine these factors and their effect on normalization.

Care by an asthma specialist. While the preventative and acute episodic health care needs of healthy children can be managed adequately by primary care providers, research shows that children with chronic illnesses, who receive additional coordinated care from specialists, experience better health outcomes, and parents were also more satisfied with the care their child received from specialists (Chin, et al., 2007; Hopia, et al., 2004; Smedley, et al., 2003). Because many parents misunderstand the chronic nature of asthma and what is needed for adequate control (Dozier, et al., 2006; Guendelman, et al., 2004), many children with asthma do not receive the treatment they need from primary care providers. A child with asthma may have many symptom-free months, and it is understandable that the parents would dismiss the importance of continued medical follow-up care during these months. Especially for families without health insurance,

primary care is difficult to afford, and care by specialists may be prohibited by cost (Chin, et al., 2007; Gupta, et al., 2006; Smedley, et al., 2003).

Differences in Maternal and Paternal Perceptions of FMS

Intrafamilial differences between maternal and paternal perceptions were included as a variable in the study to examine the influence of each parent's perceptions on the overall FMS. A component of normalization, defined as FMS and operationalized by the FaMM, was determining if one parent has the majority of responsibility for managing the child's condition, which is correlated with a lower FMS category rating; parental sharing of the caregiver burden and responsibility is associated with a higher level of normalization for the family (Knafl, 2009; Knafl, et al., 1996; Knafl, et al., 2008).

It is well-established that the characteristic and responsibility of nurturing is stereotypically a feminine characteristic (Bem, 1993; Bland, 2003; Lauzen & Dozier, 2005; Whitting & Edwards, 1973) and is most often provided by the mother within the family (Knafl & Deatrck, 2002; Sullivan-Bolya, et al., 2003; Whitting & Edwards, 1973). In a qualitative study that compared mothers' and fathers' experiences of attachment in the neonatal intensive care unit, the researchers found a distinct difference between the experiences of the parents (Fegran, et al., 2008). The mothers reported that they wanted to be involved in the care of the newborn, despite negative emotions about the seriousness of the child's condition. In contrast, the fathers preferred to remain excluded from close contact with their infant child, but when encouraged to engage in skin-to-skin contact, reported it to be a positive experience. The authors concluded that

mothers and fathers had different perspectives, but both can be encouraged to share responsibility when the infant remains hospitalized for an extended time. In a similar study of parents of very low-birthweight infants, in the first year after birth, researchers found that fathers reported significantly lower parenting self-efficacy at 3 months and 9 months, as compared to mothers (Feeley, Gottlieb, & Zelkowitz, 2007). Another difference between the parents was the fathers' reports of more received support than the mothers, at both the 3-month and 9-month intervals. However, parents reported similar levels of anxiety and perceived helpfulness of support that they received at 9 months. Based on these study findings, mothers and fathers react differently to the care demands of a child and have different perceptions. Therefore, the perspectives of both parents were considered when evaluating normalization and FMS, for families with a child with asthma.

Several researchers have focused on maternal perceptions of having a child with chronic illness (Dozier, et al., 2006; Hines & Krowchuk, 2010; Perry & Ireys, 2001), but none of these have included an intrafamilial comparison of parents' perceptions. Perry and colleagues (2003) performed a cross-sectional analysis of data collected in interviews of 159 mothers of children with one of the following chronic illnesses: (a) sickle cell disease (20%), (b) cystic fibrosis (14%), (c) diabetes (40%), or (d) asthma (31%). Maternal satisfaction was measured with the Multidimensional Assessment of Parental Satisfaction for Children with Special Needs and rated each care provider on a 1-5 scale. Paradoxically, mothers reported they relied on the child's primary care providers most often but were more satisfied with care they received from a specialist (Perry & Ireys,

2001). In a 2009 study of the effect of parental depression on proxy reported HRQOL, maternal depression was negatively correlated with maternal proxy reports, but there was no relationship between paternal depression and paternal proxy reports (Davis, et al., 2008). This study suggested that the mother's illness is reflected in their perceptions while fathers provide a more objective evaluation of HRQOL.

Knafl and colleagues (1996), Sullivan-Bolya and colleagues (2003) and Hines and Krowchuk (in progress, 2010) have utilized the FMS framework to study maternal perceptions of having a child with a chronic illness. Knafl (1996) described the FMS of 63 families with various chronic illnesses: (a) diabetes (n=36), (b) juvenile rheumatoid arthritis (n=6), (c) renal disease (n=7), (d) asthma (n=7), and (e) other chronic conditions (n=9). In this study, the researchers used opened ended interview guides to formulate a thematic overview of the five FMSs (Knafl, et al., 1996). Sullivan-Bolya performed a qualitative study of mothers of children with type-one diabetes and found that mothers use two family management approaches of strict adherence and flexible adherence but did not report using elective adherence in the daily treatment of their child's condition (Sullivan-Bolya, et al., 2003).

Based on the current literature, further investigation was needed into the differences between the perspectives and involvement of mothers and fathers who care for children with chronic illness. While families differed as to roles and responsibilities that each parent assumes in caring for their child, it was important to discover if there were gender-specific patterns within family management styles. In this study, each parent's

perspective on the family's overall FMS was measured and differences between parents by gender were investigated.

Summary

The need for further investigation into the phenomenon of the impact of a child's asthma on the family system was discussed in this chapter. Families who have a child with asthma may require help to normalize their family lives and to provide a supportive environment for the sick child and other siblings. Based on the current literature, there were gaps found in the evidence about the influence of certain variables on the family's normalization, defined as FMS. Specific factors were identified, based on the state of the science, that may contribute to the knowledge about how to support families who have a child with asthma. Because asthma is the most prevalent chronic illness in children, learning more about families who manage their child's asthma may also help families who have a child with a chronic illness. Because each parent views the impact of the child's asthma on the family differently, it was important to measure and compare the maternal and paternal perceptions of FMS. The current literature was reviewed related to chronic illness in children, specifically asthma, and significant gaps were identified in the current knowledge that forms the basis for the study. An in-depth understanding of the factors that affect families with a child with asthma is essential for nurses to help families better manage the child's condition and promote family normalization.

CHAPTER III

METHODS

The researcher investigated the maternal and paternal perceptions of FMS in families with a child with asthma. In this chapter the methods of the study are described. The study design is explicated and discussed, and data analyses plans for each research question are explained. Human subjects' protection issues are addressed and potential limitations of the study are discussed.

Study Design

In this descriptive study, the researcher investigated selected factors that have been identified from the literature review as either risk or protective factors for achieving normalization in families with children with asthma. The risk factors that were examined were: (a) child's gender, (b) child's race, (c) child's age, and (e) asthma severity. The protective factors were: (a) child's participation in an asthma education program, (b) parents' participation in an asthma education program, (c) parents' past and current experience with illness, and (d) care by an asthma specialist. Maternal and paternal perceptions of FMS were also investigated. The study used a descriptive, non-experimental correlational design to determine which of these factors were associated with normalization in families. The cross-sectional design examined data at one point in time and described the phenomenon and relationships between variables (Gliner &

Morgan, 2000). The design was appropriate because the study did not examine changes in FMS over time. A non-experimental design was implemented because the study was descriptive in nature. It was not known if the independent variables, which were the risk and protective factors influence FMS, operationalized as the FaMM score, the dependent variable. The study was correlational because it examined interrelationships between attribute variables that cannot be manipulated, and causality of the independent variables with FMS was not examined (Gliner & Morgan, 2000). Approval for the study was obtained by the institutional review board at The University of North Carolina at Greensboro (Appendix A).

Data Collection Plan

Setting

The setting for the study focused primarily in the greater Charlotte, North Carolina (NC) region, which is the largest metropolitan area in NC; however, the study was extended to include any eligible participants from North Carolina.

Population and sample

The target population was married and/or partnered couples with a child, aged 1-18 years with asthma, living in the home. The accessible population was married and/or partnered couples who lived in the greater Charlotte, NC metropolitan area and the southeastern region of the U.S. The actual sample was a convenience sample of parents of a child with asthma who completed and returned the survey. Because racial minorities

have higher rates of asthma and poorer health outcomes (Gerald, et al., 2006; Smedley, et al., 2003; CDC, 2009), it was a goal to recruit and include minority representation in the sample. Specific inclusion and exclusion criteria for the study are described in Table 2.

Table 2

Inclusion and Exclusion Criteria

Inclusion Criteria	Rationale
1. Partnered parents of children aged 1-18, who have a child with a current diagnosis of asthma. Parents may be: biological, adoptive, and/or step-parents.	1. The study focuses on children in this age range who live at home. Because this study will examine the effects of management of a chronic illness, it must be a current phenomenon for the child and family.
2. Partnered parents who live together with the child with asthma.	2. Because the concept of normalization relates to the daily management of a child's illness, both parents must reside with the child with asthma.
3. Both parents must read and understand English.	3. The instruments are in English, and because the parents will complete them without the researcher's supervision, they must be able to read and understand English.
Exclusion Criteria	Rationale
1. Parents of a child with a past history of asthma, but no current diagnosis or treatment.	1. This study will focus on the current phenomenon and family normalization.
2. Parents of a child with another chronic illness, in addition to asthma.	2. Because there may be a cumulative effect of multiple illnesses, these parents will be excluded.
3. Parents of a child who has asthma and a concurrent developmental delay.	3. The child's developmental delay may be a confounder, because it may negatively affect family normalization.

Recruitment

The sample was recruited from the greater Charlotte, NC community and the southeastern US. Participants from a pilot study who agreed to be contacted for future research were recruited for the study. These former participants provided the researcher a telephone number or electronic mail address for the researcher to contact them.

Participants also were recruited by word of mouth and with flyers (Appendix B). Flyers were given to the researcher's social and professional contacts to share with their friends who have a child with asthma. Social nomination of potential participants by other study participants and professional or social contacts was used as a recruitment strategy. The researcher telephoned or used electronic messaging to recruit participants from personal contacts and those identified by social nomination. An explanation of the study was given, and parents were asked if they would like to participate. The researcher also is trained as a parish nurse and has professional contacts with parish nurses in the greater Charlotte area. Parish nurses who work in Mecklenburg and Gaston counties distributed information about the study and recruited participants by sharing the researcher's contact information and posting flyers in their work settings.

Procedures

Parents were informed about the study procedures either in a face-to-face meeting with the researcher, via electronic messaging, or during a telephone call. The researcher asked if the parent had a child age 1-18 with asthma and if they were interested in participating in the study. If information was shared in a face-to-face interaction, the participant was given a packet to complete, which contained the research instruments.

Upon completion, the packet could be returned to the researcher either in person or via mail. Packets were mailed to those participants who were interested in participating, but who were not contacted through a face-to-face meeting. A stamped and preaddressed envelope was included for participants to return the completed instruments via mail. Parish nurses were provided with packets that they could distribute in-person to potential participants. Packets for all participants included: (a) a letter that explained the study and the enclosed surveys (Appendix C), (b) Asthma Information Survey (AIS) (Appendix D), (c) Family Management Measure (FaMM) tool (Appendix E) to be completed by the mother, (d) FaMM to be completed by the father, and (e) a self-addressed stamped envelope for return of the surveys to the investigator. Completion of the surveys was considered informed consent for participation in the study. Risk and protective factors were measured quantitatively by these instruments, along with FMS of families who have a child with asthma. According to the conceptual model, FMS was either positively or negatively affected by these factors, and the relative influence of each of these factors was determined.

To facilitate acquisition of complete data, the investigator's contact information was included in the packet, and participants were encouraged to contact the investigator by telephone or electronic mail if they had questions about the research instruments. The researcher's contact information was included in the packet to facilitate accessibility for providing clarification. Because it was unlikely that the researcher would have face-to-face interactions with both parents, it was essential to be accessible to answer questions from either parent.

Protection of Human Subjects

This study upheld the ethical principles of respect for persons, beneficence, and justice. Informed consent was implied by the completion and return of the surveys. The participants were treated as autonomous individuals, and their responses to questions were accepted as a reflection of their perceptions. There were minimal risks to participants. One potential risk to the participants was emotional distress from sharing information about a stressful subject. To minimize this risk, participants were instructed that they were voluntarily completing the surveys and could stop at any time. The time frame required to complete the surveys was less than 30 minutes, which did not pose a considerable time burden. To ensure anonymity, all measures were coded by number and stored without identifying information. The researcher maintained a master list to keep account of surveys that were distributed, but the surveys were returned without identifying information, maintaining the participants' anonymity. Data were entered using participant numbers only into a password protected file on a hard drive in a password-protected computer.

Benefits to participation outweighed any potential risks and met the criterion of justice. A direct benefit to participation was that the completion of the survey may have helped some couples discuss more freely issues related to caring for their child with asthma. Another direct benefit may include an emotional catharsis for the parents, as they were given an opportunity to share their family experiences. In addition, parents may experience a sense of understanding and support by knowing that a researcher is interested in gaining knowledge about their family in order to better help them manage

their child's asthma. Indirectly, health care providers may use the findings of the study to help other couples manage their child's chronic illness. Also, the study findings may be used by researchers to focus on aspects of family normalization for families who have an ill child. Participants were autonomous in their decisions to participate in the study and were not directly coerced. The study was approved by the institutional review board for The University of North Carolina at Greensboro as evidence of the protection of human subjects.

Instruments

While self-reported data were potential threats to reliability and validity, collecting data using self-report was appropriate to answer the research questions, because normalization is a subjective experience. Because this study was based on the parents' perceptions of normalization, their subjective responses represented their perceived reality; and therefore, the data were trustworthy and did not require validation or triangulation.

Two instruments were used in the study. The AIS was developed by the researcher for use in this study, and it consists of 14 questions with multiple choice options, 1 open-ended, and 3 closed-ended questions. The AIS was initially used in a pilot study of 28 mothers of children with asthma and was revised after use with this population (Hines & Krowchuk, 2010). Input was obtained from the participants in the pilot study, who completed the AIS in face-to-face interviews, and the AIS was revised to include more multiple choice options, rather than short answer. Also, faculty from nursing and child

development disciplines reviewed the AIS and were involved in its modification. In addition to demographic variables, the tool measured the family's risk and protective factors. Asthma severity was evaluated based on the frequency of the child's asthma symptoms, which was consistent with the most recent recommendations of the NHLBI (NHLBI, 2007). Parents reported if either the parent or child had participated in an asthma education program and provided information about the setting and length of the educational offering. Having had asthma as a child or currently having a chronic illness was reported by the parent. Care from an asthma specialist was self-reported by the parents. Questions were clearly stated to facilitate a yes/no answer whenever possible. Risk factors (gender, race, and asthma severity) were measured with questions that offered multiple choice answers. For the risk factor of age, the parents provided the child's age in years using a short-answer format. The protective factors (care by specialist, asthma education, and parental experience with asthma) were measured with yes/no questions. If the parents' response to the asthma education questions were yes, then the parents were instructed to answer 2 multiple-choice follow-up questions that focused on the length and setting of the educational offering.

The Family Management Measurement (FaMM) is a 53-item scale for parents, which was published and available for public use (Knafl, 2009). Parents responded to statements using a 5-point Likert scale that incorporates the eight conceptual dimensions of the FMS and measures parents' perceptions of their child's everyday life. The eight dimensions of FMS are as follows: (a) child identity, (b) illness view, (c) management mindset, (d) parental mutuality, (e) parenting philosophy, (f) management approach, (g)

family focus, and (h) future expectations. These eight dimensions were considered distinct entities, but also are associated and interdependent. In the FaMM tool, the eight dimensions were represented by six subscales within the instrument that measure the parents' ease or difficulty in coping with the child's condition. The three scales indicative of ease in managing the child's illness are: (a) child's daily life, (b) condition management ability, and (c) parental mutuality. The remaining three scales indicative of more difficulty with managing the child condition are: (a) condition management effort, (b) family life difficulty, and (c) view of condition impact (Knafl, 2009). Because all parents were partnered and/or married, they completed all six scales independently.

Higher scores on three of the FaMM subscales (child's daily life, condition management ability, parent mutuality) were indicative of normalization for the family, despite having a child with a chronic illness, while higher scores on the remaining three subscales (condition management effort, family life difficulty, view of condition impact) were indicative of difficulty with normalization. Maternal and paternal perceptions of FMS were measured in order to gain a more precise understanding of the family's normalization from differing perspectives. Previously established internal consistency reliability (ICR) for the FaMM are: (a) for mothers (0.72-0.90), (b) for fathers (0.73-0.91), and (c) inter-parental correlation (0.33-0.59), p value < 0.01 (Knafl, 2009). The specific ICR for each of the five scales are provided in Table 3.

Table 3

Internal Consistency Reliability (ICR) of Six Scales within FaMM

Scale	ICR for Mothers	ICR for Fathers	Inter-parental correlation (ρ value)
Child's Daily Life	0.76	0.79	0.55 (<0.01)
Condition	0.72	0.73	0.33 (<.01)
Management Ability			
Condition	0.74	0.78	0.58 (<0.01)
Management Effort			
Family Life	0.90	0.91	0.59 (<0.01)
Difficulty			
Parental Mutuality	0.79	0.75	0.44 (<0.01)
View of Condition	0.73	0.77	0.58 (<0.01)
Impact			

Test-retest reliabilities range from 0.71 - 0.94, and the specific values for each of the five scales is provided in Table 4. Validity of the instrument has also been evaluated. Construct validity was ascertained with correlations with established measures of the McMaster Family Assessment Device and the Functional Status II instrument (FSM II), with generally moderate strength of correlations (0.16-0.64) (Knafl, 2009). These correlational measures are presented in Table 5.

Table 4

Test-retest Reliability of Six Scales within FaMM

Scale	Test-Retest Reliability
Child's Daily Life	0.83
Condition Management Ability	0.79
Condition Management Effort	0.81
Family Life Difficulty	0.94
Parental Mutuality	0.71
View of Condition Impact	0.87

Table 5

Correlation of Six Scales with established Measures

	McMaster Family Assessment	Functional Status II	Eyberg Child Behavior Inventory Problem/Intensity
Child's Daily Life	-0.21	0.39	-0.21/-0.22
Condition Management Ability	-0.35	0.32	-0.23/0.25
Condition Management Effort	0.16	-0.33	0.13/0.17
Family Life Difficulty	0.38	-0.45	0.31/0.33
Parental Mutuality	-0.64	0.20	-0.25/-0.28
View of Condition Impact	0.22	-0.32	* 0.09/0.15

ρ values < 0.01 for all correlations except * $\rho = 0.03$

The scoring of the FaMM may be achieved by calculating a total score, or by calculating individual scale scores. For the study both total and subscale scores were calculated. In order to obtain a valid score for each subscale, seventy percent of the items

must receive valid responses. The minimum number for each scale is as follows: (a) child's daily life scale: 4 of 5 responses, (b) condition management ability scale: 9 of 12 responses, (c) condition management effort scale: 3 of 4 responses, (d) family life difficulty scale: 10 of 14 responses, (e) parental mutuality scale: 6 of 8 responses, (f) view of condition impact scale: 7 of 10 responses (Knafl, 2009).

Maternal and paternal total and subscale scores were determined. The FMS for the family was calculated by adding the mothers and fathers FaMM scores. The FaMM scale included reverse coded items that were scored accordingly. The six specific subscale scores were determined for each parent (Knafl, 2009). Reliability of the FaMM was calculated by determining the Cronbach's alpha coefficient for the instrument and its use in this sample.

Data Analyses Plan

The initial step in the data analysis was to clean the data, which included the management of missing data. As data were entered into the Statistical Package for Social Sciences (SPSS) version 18 computer software, responses were confirmed with the hard data. If a response was missing, it was coded as missing, and the participant was included in the dataset. Hard data were stored in a locked cabinet in the researcher's locked office. Statistical analyses were performed on a password-protected computer in the researcher's office.

The data analysis plan included a method for managing outliers. First, the investigator verified the outlier(s) noted in SPSS with the hard data. Once validated that

the data were accurate, the statistical analyses were executed with SPSS computer software, including the outlier(s). Next, the statistical analyses were run without the outlier(s) to evaluate for a significant change. Outliers were determined by standardized residual values of less than -3.0 or greater than 3.0 (Tabachnick & Fidell, 2007).

Because outliers may contain valuable information about the phenomenon of interest, they were included, unless one data point was responsible for a skewed result that did not accurately reflect the sample.

Once data were validated as accurate, statistical analyses were executed. Data analyses began with determining the descriptive statistics for each variable. Mean, standard deviation, minimum, and maximum for the total cases were calculated for each continuous variable. Proportions were determined for nominal level variables. Frequencies were calculated for each variable and examined for outliers. Outlier(s) were managed as described previously. Measures of central tendency were obtained for all variables.

It was important to identify potential confounding factors in the study and to adjust for them statistically. Age was the most prominent confounding factor. There was a wide age range and developmental abilities represented by children ages 1-18, whose parents were eligible to participate in the study. Because children mature at varied rates, children of the same age may have vastly differing abilities in assuming self-management responsibilities for asthma, which may impact the family's ability to normalize. When analyzing the data, the variable age was controlled for statistically in the regression model, and the results were not affected by this confounding factor.

The specific data analysis for each of the research aims and questions is outlined below.

Aim (1): To determine the families' levels of normalization, defined as FMS, and operationalized by the FaMM Scale score, in families with a child with asthma.

Q 1: What were the overall FMS scores, based on the maternal and paternal FaMM scores, of families who have a child with asthma?

To determine the FMS scores for each family, the maternal and paternal FaMM scores were calculated and totaled for each family. The mean, standard deviation, minimum, and maximum for the total cases, individually and paired by couple, were calculated.

Aim (2): To explore the relationship among several variables: (a) child's gender, (b) child's race, (c) child's age, (d) asthma severity, (e) child's participation in an asthma education program, (f) parent's participation in an asthma education program, (g) parent's past/current experience with asthma, and (h) care by an asthma specialist on the variable, family normalization, defined as FMS, and operationalized as the FaMM score, of families who have a child with asthma.

Q2: What was the influence of the potential risk factors of: (a) child's gender, (b) child's race, (c) child's age, and (e) asthma severity on the variable, family normalization, defined as FMS, and operationalized as FaMM score?

Independent variables were correlated and checked for multicollinearity. If two variables were correlated at 0.85 or higher, one variable was eliminated from the multiple regression analysis, or separate models were created. The tolerance level and variance

inflation factors (VIFs) were calculated to evaluate for multicollinearity. A tolerance value of less than 0.10 and VIFs great than 10 were used to define multicollinearity and resulted in elimination of variable(s) from the model (Tabachnick & Fidell, 2007).

Frequencies were run for each variable and outlier(s) were managed as described earlier.

Data were checked for meeting the assumptions of linear regression with an analysis of the residuals using scatterplots to assess for: (a) normal distribution, (b) homoscedasticity, and (c) linearity. If an assumption was not met, then the necessary mathematical transformations were performed. Variables were added into the model as a block, which is consistent with the study's conceptual model of risk and protective factors. Using an assumed alpha of $p < 0.05$, only the significant variables were added into a subsequent multiple regression model to determine the specific amount of variance in total FMS explained by each variable (Munro, 2005; Polit, 2009).

Q3: What was the influence of the protective factors of the: (a) child's participation in an asthma education program, (b) parent's participation in an asthma education program, (c) parent's past and current personal experience with asthma, and (d) care by an asthma specialist on the outcome variable, family normalization, defined as FMS, and operationalized as FaMM score?

Data analyses were similar to the analysis previously described. The independent variables of child and parent's participation in an asthma education program were checked for multicollinearity, and mathematical transformations were performed as necessary. After checking for assumptions of linear regression, variables were added into the model as a block. Using an assumed alpha of $p < 0.05$, only the significant variables

were added into a subsequent multiple regression model to determine the specific amount of variance in total FMS explained by each variable (Munro, 2005; Polit, 1996).

Aim (3): Compare the maternal and paternal perceptions of normalization, defined as FMS, and operationalized as the FaMM score in families who have a child with asthma.

Q4: What was the relationship between maternal and paternal perceptions of normalization, defined as FMS, and operationalized by FaMM scores in families who have a child with asthma?

Distributions of the maternal and paternal scores were assessed for normal distribution using visual evaluation of histograms. If data met the assumption of normal distribution, a Pearson r was conducted to assess for a significant relationship. Based on an assumed alpha level of ≤ 0.05 , the null hypothesis was rejected if the Pearson r statistic was statistically significant.

Q5: What was the difference in parent's perceptions of normalization, defined as FMS, and operationalized as mean maternal and paternal FaMM scores in families who have a child with asthma?

The independent variables of maternal and paternal scores on FaMM were checked for normal distribution using histograms. If data met the assumption of normal distribution, a 2-tailed paired t -test was performed. Based on an assumed alpha level of ≤ 0.05 , the null hypothesis was rejected if the t statistic was statistically significant.

Q6: What were the maternal and paternal perceptions of normalization, defined as FMS, and operationalized by the six subscale scores of the FaMM?

Maternal and paternal FaMM scores on each of the six subscales were calculated for each family. The mean, standard deviation, minimum, maximum, mode and range for the total cases, individually and paired by couple, were calculated.

Q7. What was the relationship between maternal and paternal perceptions of normalization, defined as FMS, and operationalized as their scores on each of the six subscales of the FaMM?

Distributions of the maternal and paternal subscale scores were assessed for normal distribution. If data met the assumption of normal distribution, a Pearson r was conducted to assess for a significant relationship. Based on an alpha level of ≤ 0.05 , the null hypothesis was rejected if the Pearson r statistic was statistically significant.

Q8. What was the difference in maternal and paternal perceptions of normalization, defined as FMS, and operationalized as the mean scores on the six subscales of the FaMM?

The variables of maternal and paternal scores on the six subscales of the FaMM were checked for normal distribution. If data met the assumption of normal distribution, a 2-tailed paired t -test was conducted on each of the paired subscale scores. Based on an alpha level of ≤ 0.05 , the null hypothesis was rejected if the t statistic was statistically significant.

Power Analyses

Based on the nQuery computer program, for 11 variables, a sample size of 39 paired participants ($N = 78$) was needed for a statistical power of 0.80, correlational analysis with an alpha of 0.05, and an effect size of 0.20 (Gatsonis & Sampson, 1989).

Internal Validity

The study included a reasonable plan for data collection. However, there were several potential threats to internal validity. Because this was a cross-sectional study, maturation was not a threat. Repeated instrumentation was a potential threat to validity for a proportion of the mothers in the sample who were recruited from a previous study and had completed the FaMM within a 6-month period. However, the FaMM is a 53-item sophisticated instrument that included an adequate number (18 items) of reverse coded items, so it was unlikely that the mothers' responses were influenced by their previous exposure to the tool. Using one person to collect and analyze the data decreased the threat of instrumentation. History and environmental events were threats to internal validity for the study. Unrelated events may have occurred that affected the parents, and thereby, affected their responses to the survey questions. It was not possible to control for these unrelated events; they are generally random and would not affect the whole group. Parents may have been affected by environmental factors, such as distraction and the effect of being in a study, and these may have affected their responses.

External Validity

The design for the study had several threats to external validity, despite producing data from measuring instruments that should have accurately reflected the participants' risk and protective factors, along with their perceptions of family management style. However study results have limited generalizability for several reasons. First, the accessible population did not represent the theoretical population of families who have a child with asthma. In addition, using a convenience sampling method from the accessible population was a threat to external validity. Because a significant proportion of the potential participants participated in a prior study with the investigator, a higher than usual response rate was anticipated, making oversampling unnecessary. Random sampling was not possible because the participants must meet narrow inclusion criteria with attribute variables. The use of a nonprobability convenience sample was a significant threat to external validity, and generalization from the nonrandom sample may be limited (Polit, 2009).

The external validity of this study had strength from an ecological perspective. The setting and conditions for the study were as natural as possible because the participants were able to complete the survey at their convenience and without the investigator present. The results of the study were limited to this sample and may have limited generalizability to families caring for children with other chronic conditions.

Limitations

There were several potential limitations to this study. First, the study used a convenience sample from one geographic area and may not reflect the family management styles of parents from other geographic locations; therefore, the findings of this study may not be generalizable to other populations. Additionally, the sample was not representative of the larger theoretical sample with regard to demographics. Parents who completed the survey may have been different from parents who chose not to participate. Specifically, parents who participated may have had concerns about their child's asthma that prompted them to respond. Distributing the surveys to the parents to complete did not ensure that the mother and father were the persons who provided the information. Lastly, because the study included only married and/or partnered parent dyads, these results may not be generalizable to different family configurations, such as single parent families.

Summary

A cross-sectional, descriptive, non-experimental study was conducted to determine factors affecting family coping for families with a child with asthma. A targeted convenience sample of 39 parent dyads was recruited from the greater Charlotte, NC area. The research study was approved by the institutional review board of The University of North Carolina at Greensboro. Two instruments were distributed by the investigator. Data analyses included descriptive statistics, as well as various multiple

regression models that determined the influence of certain risk and protective factors on family normalization using FMS as a theoretical foundation.

CHAPTER IV

RESULTS

Results of the data analyses for the study are reported in this chapter. The preliminary examination of the data includes: an explanation of how data were managed, a discussion of the reliability of instruments, and descriptive analyses of the sample. Specific analysis for each research question is addressed. Additional statistical analyses are provided, along with a summary of results.

Preliminary Examination of Data

Before addressing the specific research questions, the preliminary examination of the data obtained from the study participants is discussed. Reliability of the two instruments, the Asthma Information Survey (AIS) and the Family Management Measure (FaMM), will be provided.

Management of Data

Participants completed written surveys and returned them to the researcher, either in person or by mail in a self-addressed stamped envelope. Data were identified only by the order in which the surveys were returned to the researcher and contained no other identifying information, so that anonymity of the study participants could be maintained. A total of 53 study packets were distributed to parent dyads that met the

inclusion criteria and agreed to participate in the study. The required proposed sample size of 39 parent dyads was exceeded by 4 parent dyads, with a total of 43 parent dyads (86 study participants) returning the surveys. Data were coded, entered, and analyzed using the Statistical Package for Social Sciences (SPSS) version 18.0 (SPSS, 2010).

As data were entered into the SPSS computer program, responses were checked against the raw data collection forms for accuracy. Frequencies were calculated for all variables to check for missing data and extreme values. If a response was missing on the AIS, it was coded as missing, and the participant was included in the dataset. For the FaMM, three of the participants (one mother and two fathers) had one missing value out of 53 values. The number of required items for each subscale of the FaMM was met, despite these 3 missing values. For each of the missing values, the mean score for that particular item on the FaMM was substituted for the parent's missing response (Polit, 2009; Tabachnick & Fidell, 2007).

The nominal demographic data were coded into categories and included the variables of: child's race, child's gender, daily asthma medication, care by a specialist, health insurance, participation in an asthma education program, parents' asthma status, parents' educational level, and desire to share more information about their child's asthma (Appendix E). Statistics related to age of the children in the study are provided in Table E.1 (Appendix E), and additional demographic descriptors of the study sample are provided in Table E.2 (Appendix E). Variables that were related to the child's asthma severity and management were also categorized and are presented in Tables E.3 (Appendix E).

Data were assessed for normality; skewness and kurtosis statistics were evaluated, as shown in (Appendix E, Table E.2). Based on this evaluation, the variables were determined to have normal distributions. Outliers were noted in scatterplots that represent the data points in relation to a normal distribution (Appendix F, Figures F.1-F.8) and verified any outliers with the raw data. Because most of the variables were categorical, the chance of outliers was minimal. However, despite the preponderance of categorical level data, one outlier for the variable of asthma severity was identified. Analyses were run with and without this outlier to evaluate its effect on the models. Because outliers contain valuable information about the phenomenon of living with a child with asthma, this case was included in the final analysis.

Distributions of the dependent variables were assessed for normality as shown in histograms (Appendix G). After verifying normal distribution of the variables using plot analyses, no data transformations were necessary. The FaMM instrument has a potential score for each parent of 53-265, and scores for a family may range from 106-530. There were no scores that were over three standard deviations from the mean for maternal, paternal, or family FaMM scores; therefore, there were no identified outliers (Mertler, 2005; Tabachnick & Fidell, 2007).

Reliability of Instruments

AIS was developed initially to be used with families who have a child with asthma to collect information related to the child with asthma, the family system, and specific aspects of the child's asthma condition and treatment regimen. Based on a review of the literature, specific characteristics of the child and family were included that may

impact asthma outcomes, such as: child's age, child's race, health insurance status, parents' education levels, and number of children in the home. In addition, the instrument included aspects that described the child's asthma severity and potential impact on the family's daily life, such as: daily asthma medication, care by an asthma specialist, and frequency of asthma symptoms. It was important to evaluate the impact of asthma education for parent and/or child; therefore, the AIS included questions to identify the source and length of asthma education programs that the study participants had attended. The majority of questions were posed using multiple choice options, allowing the parents to choose an answer. The following information was gathered using open-ended questions: child's age, length of parental cohabitation, and name of asthma medications.

Based on pilot study findings in which mothers of children with asthma were interviewed, the AIS was refined for the present study. Pertinent information related to the family's demographic characteristics, the child's asthma status, and the targeted risk and protective factors that were evaluated as independent variables in this study were included in the AIS. With those aims, the parents were asked to respond to questions related to these factors and were also given an opportunity to provide additional information in a narrative format regarding caring for their child's asthma.

Several specific changes were made to the AIS instrument based on pilot study findings. First, the age of the parents was no longer included in the demographic information, because it was not identified in the literature as germane to the concept of family normalization. Also, mothers who participated in this pilot study were told that

they did not have to answer any questions that they did not want to, and two of the participants did not provide their age on the survey (Hines & Krowchuk, 2010). Next, a question about when the child was diagnosed with asthma was also omitted from the revised AIS, based on the lack of reliability in the responses to this question in the pilot study. In the pilot study, respondents frequently gave a broad time frame for the length of diagnosis, such as 2-3 years ago, and many included wording such as, about a year ago, that did not allow for specificity in measurement or categorization for accuracy in analyses. While the researcher had initially planned to investigate if length of diagnosis was a risk or protective factor, this variable was addressed in a related measure of the child's age, which often corresponds roughly to length of diagnosis (Barton, et al., 2005; Spagnola & Fiese, 2010; Sullivan-Bolya, et al., 2003). Also, income levels of parents were not included, because health insurance status and parental educational levels were considered adequate reflections of available socioeconomic resources (Levy, et al., 2006; Miller, 2000; Sin, et al., 2003). For future studies, the AIS can be further adapted and targeted to specific populations and may include additional questions.

The FaMM was the second instrument completed by study participants. The FaMM was developed to provide a quantitative measure of the concept of normalization, which is defined as FMS, and operationalized as the FaMM score (Knafl, 2009). The FaMM offered a measure of how families with a child with asthma manage everyday family life, while caring for their child's condition. Key aspects of family management are reflected in the instruments' six subscales: child's daily life, condition management

ability, condition management effort, family life difficulty, view of condition impact, and parent mutuality. Parents' scores on the six subscales of the FaMM were representative of factors that support or impede the family's ability to normalize, or provide a normal family life, despite having an ill child.

Post-hoc analysis of the FaMM revealed a Cronbach's alpha level of 0.7 for the 86 parents who answered 53 items. As previously noted, the FaMM is a 53-item scale using a 1-5 Likert scale and includes 18 reverse-coded items. It is postulated that the length of the instrument may have been burdensome, even though the participants in a pilot study were able to complete the tool in less than 30 minutes. These participants completed the FaMM in an environment that limited distractions. It is also possible that the large (18 items, 34%) percentage of reverse-coded items may have been confusing to some participants. The Cronbach's alpha level was calculated at 0.8 when the reverse coded items were deleted, which is evidence that these reverse-coded items may have been unstable, and thus contributed to lower internal consistency (Weems & Onuluegbuzie, 2001). Specifically, Cronbach's alpha levels for each of the FaMM's six subscales are provided in Table 6 below. It is evident that there is great variance in the number of items for each scale, which may contribute to the wide variation in calculated Cronbach's alpha levels (0.2-0.8).

Table 6

Cronbach's Alpha Levels for Six Subscales of the FaMM

Subscale	# of Items	# Reverse-Coded	Cronbach's alpha level
*1. Child's Daily Life Scale	5	3	0.2
*2. Condition Management Ability Scale	12	4	0.5
**3. Condition Management Effort Scale	4	1	0.8
**4. Family Life Difficulty Scale	14	3	0.7
*5. Parent Mutuality Scale	8	4	0.7
**6. View of Condition Impact Scale	10	3	0.6

* subscale is positively correlated with normalization

** subscale is negatively correlated with normalization

In this study sample, there was low internal reliability on the parents' scores on Subscale one (0.2) of the FaMM, which depicts the child's ability to have a normal daily life despite their illness. Also, the Cronbach's alpha for Subscale two (0.5) was also below an acceptable level (desired Cronbach's alpha ≥ 0.6), and this subscale addresses the parents' perceptions of their abilities to manage their child's illness. Despite these identified reliability issues, the remainder of the FaMM's subscales are equal to or above an acceptable level of psychometric instrument reliability. Also, the three subscales that are positively correlated with normalization had a wide range of Cronbach's alpha scores (0.2-0.7), with a calculated average Cronbach's alpha of 0.5. For the three subscales that are negatively correlated with normalization, there was much less variance in the values (0.6-0.8), and the calculated Cronbach's alpha for these scales was 0.7, which is at an acceptable level of reliability. The overall internal

consistency of the FaMM was acceptable with a Cronbach's alpha of 0.7. Also, it was important to use the FaMM with families who had a child with asthma, because the tool had not been used with this population exclusively in prior studies.

Characteristics of the Sample

First, descriptive analyses were performed on the demographic data. In Table E.1 (Appendix E), the results of descriptive analyses are shown for the variable of child age, with the associated minimum, maximum, mean, frequencies, and percentages. The variable exhibits a normal distribution which is represented in scatterplot evaluation (figure 3) and is also confirmed by evaluation of the Mahalanobis distance (mean 0.977). The mean age of the children in the sample was 10.17, which is also supportive of a normal distribution for the variable age, when the targeted sample was children aged 1-18 who have asthma. Males were slightly overrepresented, as compared to the general population (55.8% of the study sample); but because asthma is more prevalent in males, it is appropriate to have more males in the study sample.

Additionally, asthma is more prevalent in non-White children, and it was important to recruit these families for the study. In the sample, 79.1% of the participants were White, which is an accurate reflection of the percentage of Whites (79.6%) in the general population of the U.S. (U.S. Census Bureau, 2010). Similarly, 11.8% of the sample were African American children with asthma, which is a close approximation of the percentage of African Americans (12.9%) in the general U.S. population (U.S. Census Bureau, 2010). A majority of families in the sample (65%) were comprised of

3-4 members and included the parents, the child with asthma, and up to one sibling. The families in the study were smaller than the current average U.S. family that includes parents and 1.86 children ("Family structure and children's living arrangements: Percentage of children ages 0–17 by presence of parents in household and race and Hispanic origin, 1980–2009," 2009).

While being a biological parent of a child with asthma was not an inclusion criterion for the study, the overwhelming majority of mother (93%) and fathers (90.7%) were the biological parents. The study sample was also comprised of parents with high educational levels; 81.4% of the mothers had at least a college degree, and 69.8% of the fathers had this same level of education. The majority of the parents in the study reported the frequency of their children's asthma symptoms as mild intermittent (90.7%). Because this rating system is based on guidelines published by the NHLBI in 2007, comparison data, based on the re-design of the classification system, are not yet available (NHLBI, 2007). Despite rating asthma severity as mild, a significant number of the children (37.2%) received care from an asthma specialist, in addition to the child's primary care provider. This high rate of care by a specialist may be related to having insurance coverage, as 100% of the sample reported some type of health insurance for their child. Also, over half of children (51.2%) took daily medication to manage their asthma, which may mean that their asthma was being managed well with medication that prevented the asthma from being classified with worse severity. Despite their obvious access to health care and educational resources, only 16.3% of the children and 32.6% of the parents had received any asthma education.

Descriptive Statistics of the Instrument

The AIS was completed by each of the 43 parent dyads and was comprised of short answer and multiple choice questions. An additional half page was provided for the parents to write a narrative about caring for their child with asthma, and 24 parents (55.8% of the sample) provided additional information. The FaMM was completed by each of the parents in the study and is comprised of 53 items that are rated using a 1-5 Likert scale. The six subscales within the FaMM are displayed in Table 7, with the numbers of items per subscale. The mean scores for each of the six subscales are presented in Table 7. The mean for the three subscales that are positively correlated with normalization is a score of 75, and the mean for the three subscales that are negatively correlated with normalization is a score of 84.

Table 7

Range of Scores for Six Subscales of FaMM

Subscale	# of Items	Min Score	Max Score	Mean
1. Child's Daily Life	5	5	25	15
2. Condition Management Ability	12	12	60	36
3. Condition Management Effort	4	4	20	12
4. Family Life Difficulty	14	14	70	42
5. Parent Mutuality	8	8	40	24
6. View of Condition Impact	10	10	50	30

Research Questions

The specific analyses for each of the research aims and questions are discussed below.

Aim (1):

To determine the families' levels of normalization, defined as FMS, and operationalized by the FaMM scores, in families with a child with asthma.

Research question one. Q1. What were the family FaMM scores, based on maternal and paternal FMS scores, of families who have a child with asthma?

Each of the 43 parent dyads completed the AIS, and each of the 86 parents completed the FaMM instrument. The calculated minimum, maximum, mean, standard deviation, mode and range for the maternal and paternal scores on the FaMM are represented in Table 8. Out of a possible score of 265 on the FaMM, the mothers' scores were higher as compared to the fathers' scores. For parental dyads/families, the possible total score is 530, and the mean for the study sample was 289.35 ± 15.9 , indicating that the families in the sample had a mean FaMM score that was lower than the instrument mean FaMM score of 318. Each subscale must be evaluated separately in order to analyze if this score reflects success or difficulty with normalization for these families.

Table 8

Maternal and Paternal FaMM Scores

FaMM Score	Mothers	Fathers	Families
Mean (SD)	150.49 \pm 10.03	146.63 \pm 9.12	289.35 \pm 15.94
Median	152.0	146.0	292.0
Mode	155.0	144.0	272.0
Skewness	-0.14	-0.33	-0.50
Kurtosis	-0.51	0.98	0.95
Range	42	47	85
Minimum	129	120	246
Maximum	171	167	331

The skewness and kurtosis statistics are supportive evidence that the maternal, paternal, and family FaMM scores are normally distributed, in addition to the histograms provided in figures 16-18 (Appendix G). While the range of scores was limited by the 1-5 Likert scoring of the FaMM, the parents' scores exhibited the necessary variability and normal distribution for statistical rigor. Maternal FaMM scores displayed a higher overall mean, along with a higher minimum and maximum score, as compared to the paternal FaMM scores. No published studies were found for comparison that provided both parents' FaMM scores; therefore, there is no benchmark for evaluation of the FaMM scores for this study sample in comparison to others. In the pilot study, mean FaMM scores for a sample of 28 mothers who had a child with asthma was 122.96 ± 12.6 out of a possible range of 45-225 (Hines & Krowchuk, 2010). Mothers in the pilot study only completed 5 of the six subscales because the

parent mutuality subscale is for partnered parents only. Because the pilot study did not include fathers, mothers in the study did not complete the parent mutuality subscale.

Aim (2):

To explore the relationship among the variables: (a) child's gender, (b) child's age, (c) child's race, (d) asthma severity, (e) child's participation in an asthma education program, (f) parent's participation in an asthma education program, (g) parent's past/present asthma experience, and (h) care by an asthma specialist on the variable, family normalization, defined as FMS, and operationalized as the FaMM score of families who have a child with asthma.

Research question two. Q 2. What was the influence of the potential risk factors of: (a) child's gender, (b) child's race, (c) child's age, and (d) asthma severity on the variable, family normalization, defined as FMS, and operationalized as the family's FaMM score?

Data met the following assumptions of linear regression with an analysis of the residuals using scatterplots (Appendix E): normal distribution, homoscedasticity, and linearity. Therefore, no transformations were necessary, and the variables were added into the model as a block. The overall model had an r^2 of .18, an adjusted r^2 of 0.1, $p = 0.095$. Of the four risk factors, only asthma severity had a statistically significant p value ($p = 0.006$), with a Beta coefficient of 0.424. Therefore, for each unit change in asthma severity category, the FaMM score for the family decreases 42.4%. The Beta coefficients with corresponding 95% CI's and p values, along with Durbin-Watson values, which are evidence of each variable's normal distribution, are provided in Table

9. Although asthma severity had a significant p value, it has a large associated confidence interval, which decreases the specificity of the variable's predictive ability.

Table 9

Regression Model for Potential Risk Factors Related to Normalization

Variable	Standardized Beta	p value	95% CI	Durbin-Watson
Child's age	-0.17	0.25	-1.75, 0.47	1.62
Child's gender	-0.05	0.75	-10.87, 7.91	1.58
Child's race	-0.15	0.32	-8.06, 2.72	1.51
Asthma severity	0.43	0.006*	4.02, 22.21	1.52

* statistically significant ($p \leq 0.05$)

Research question three. Q3. What was the relative influence of the potential protective factors of: child's participation in an asthma education program, either parent's participation in an asthma education program, either parent's past or present experience with asthma, and care by an asthma specialist on the variable, family normalization, defined as FMS, and operationalized as the family FaMM scores?

Within the constraints of categorical and ordinal data, the following assumptions of linear regression were met with an analysis of the residuals using scatterplots (Appendices E.5-E.8): normal distribution, homoscedasticity, and linearity. Therefore, no transformations were necessary, and the variables were added into the model as a block. The model had an r^2 value of 0.137 but was not statistically significant with a p value of 0.22. Of the four protective factors, no variables had a statistically significant

p value, using the a priori designation of significance at $p \leq 0.05$. Beta coefficients with corresponding 95% CI's and p values, along with Durbin-Watson values, which are evidence of each variables normal distribution, are provided in Table 10.

Table 10

Regression Model for Potential Protective Factors Related to Normalization

Variable	Standardized Beta	p value	95% CI	Durbin-Watson
Asthma Ed for child	-0.21	0.26	-19.60, 5.37	1.59
Asthma Ed for parent	0.21	0.21	-4.27, 19.19	1.59
Either parent have/had asthma	0.18	0.29	-4.98, 16.19	1.59
Care by asthma specialist	0.30	0.06	-0.47, 20.26	1.72

Aim (3):

Compare the maternal and paternal perceptions of normalization, defined as FMS, and operationalized as FaMM scores in families who have a child with asthma.

Research question four. Q 4. What was the relationship between the maternal and paternal perceptions of normalization, defined as FMS, and operationalized as the FaMM scores in families who have a child with asthma?

Distributions of the maternal and paternal scores were assessed for normal distribution and were normally distributed as shown in the histograms (Appendix G). A Pearson r correlation was performed for the paired maternal and paternal FaMM scores, with a resulting Pearson correlation of 0.532 ($p < 0.001$, 2-tailed), which shows a strong positive correlation between the scores. This finding is not surprising, because

the parents in the study are married partners with a mean length of cohabitation of 14 years (± 5.8). This study finding also confirms that the parents' perceptions of how the family is managing their child's asthma are strongly associated; however, the findings are also statistically different, as revealed in the results of the next research question.

Research question five. Q5. What was the difference in the parents' perceptions of normalization, defined as FMS, and operationalized as the mean maternal and paternal FaMM scores?

After meeting the assumption of normal distribution by assessing histograms, a paired *t*-test was conducted using the paired maternal and paternal FaMM scores. The difference between the mean maternal and the mean paternal scores was statistically significant, based on a 2-tailed paired *t*-test with a *t* statistic of 2.73 ($df = 42$, $p = .009$). Therefore, parents have different perceptions of how well the family is able to provide a normal family life for its members while caring for a sick child. This disagreement between the parents may be a potential source of stress for couples and further impair their ability to lead what they consider normal lives.

The following questions examine the FaMM subscale scores for the mothers and fathers, which lend more specificity to the components of the family management styles score and provides insight into normalization and its eight dimensions.

Research question six. Q6. What were the maternal and paternal perceptions of normalization, defined as FMS, and operationalized as the six subscale scores of the FaMM?

The six subscales of the FaMM reflect the eight dimensions of family management styles and are important to better understanding the impact of having a child with asthma on the family system and its ability to normalize. The calculated minimum, maximum, mean, standard deviation, mode and range for the maternal, paternal, and family scores on the six subscales of the FaMM are represented in Table 11.

Table 11

Descriptive Statistics for Six Subscales of the FaMM

Subscale/Parent/Family Range	Mothers Mean (SD)	Fathers Mean (SD)	Families Mean (SD)
*1. Child's Daily Life (5-25)/(10-50)	22.79 (2.9)	23.07 (2.67)	45.86 (4.18)
*2. Cond. Mt. Ability (12-60)/(24-120)	52.56 (6.04)	52.89 (5.56)	105.45 (9.53)
**3. Cond. Mt. Effort (4-20)/(8-40)	8.07 (3.04)	7.42 (2.79)	15.49 (5.36)
**4. Fam. Life Diff. (14-70)/(28-140)	18.40 (4.51)	18.40 (4.34)	36.79 (7.65)
*5. Parent Mutuality (10-50)/(20-100)	32.42 (6.34)	33.49 (4.10)	65.91 (9.11)
**6. View Cond. Impact (8-40)/(16-80)	16.56 (4.17)	16.22 (4.51)	32.78 (7.26)
* positively correlated with normalization			
** negatively correlated with normalization			

As shown in Table 11, the mothers' scores are higher than the fathers' on the following subscales: subscale 3/condition management effort subscale and subscale 6/view of condition impact subscale. The mothers' scores on subscale 3 reflect their perceptions of increased time and work that required to manage their child's asthma in the condition management effort subscale. The higher scores on subscale 6 are consistent with this previous finding and suggest that mothers view asthma as having

more serious implications for their child in the future. Interestingly, the mothers' and fathers' mean scores were equivalent on the family difficulty life scale, which is a 14 item scale and reflects how their child's asthma makes life more difficult for the family and all its members.

Similarly, there was also a pattern among the three subscales in which the mothers' mean scores were lower, as compared to the fathers' scores: subscale 1/ child's daily life scale, subscale 2/condition management ability subscale, and subscale 5/parent mutuality. Because lower scores on subscales 1 and 2 are associated with less normalization by the family, the mothers' scores reflect that they view asthma as having more of an impact on the family in these specific areas. According to subscale 1 scores, mothers in the study perceived that asthma decreases the child's ability to have normality in daily life. In the closely related subscale 2, the mothers' perceptions were indicative of feelings that asthma is a difficult condition to manage. Additionally, the low maternal scores on subscale 5/parent mutuality were indicative of perceptions that mothers do not receive support from their spouse in managing their child's asthma and that their spouse does not share views with them about daily asthma management.

Research question seven. Q7. What was the relationship between the maternal and parental perceptions of normalization, defined as FMS, and operationalized as scores on each of the six subscales of the FaMM?

Distributions of the maternal and paternal subscale scores were determined to be normally distributed, within the constraints of the 1-5 Likert responses on the FaMM, as shown in the histograms (Appendix G). A Pearson r correlation was conducted on

the paired maternal and paternal subscale FaMM scores, with a resulting Pearson r correlation for each pair. Correlations and their statistical significance are shown in Table 12.

Table 12

Pearson r Correlations for FaMM Subscales

Subscale	Pearson r Correlation	p value
1 Child's Daily Life	0.128	0.42
2 Condition Management Ability	0.351	0.021 *
3 Condition Management Effort	0.690	<0.001 *
4 Family Life Difficulty	0.490	0.001 *
5 Parent Mutuality	0.499	0.001 *
6 View of Condition Impact	0.400	0.008 *

* significant at the $p \leq 0.05$ level

As shown in Table 12, all of the six subscale scores for mothers and fathers are significantly correlated, except for subscale one, which is representative of the parents' perceptions of everyday life with their child. These findings support that FaMM is an accurate measure of family management styles. While maternal and paternal perceptions were not consistent in the child's daily life subscale, it is reasonable that parents would have differing levels of involvement on a daily basis with the child with asthma that are reflected in this area of family management styles.

Research question eight. Q8. What was the difference in the maternal and paternal perceptions of normalization, defined as FMS, and operationalized as the mean scores on the six subscales of the FaMM?

After meeting the assumption of normal distribution by assessing histograms, a paired *t*-test was conducted using the paired maternal and paternal subscale FaMM scores. The difference between the maternal mean and the paternal mean scores on each of the six subscales was measured and are shown in Table 13.

Table 13

Paired t-test for FaMM Subscales

Subscale	Mean difference (SD)	<i>t</i> statistic/df	<i>p</i> value
1 Child's Daily Life	-0.27 (3.68)	-0.497/42	0.622
2 Condition Management Ability	-0.332 (6.61)	-0.329/42	0.744
3 Condition Management Effort	0.651 (2.31)	1.85/42	0.071
4 Family Life Difficulty	0 (4.48)	0.0/42	1.0
5 Parent Mutuality	1.06 (5.57)	-1.25/42	0.217
6 View of Condition Impact	0.338 (4.76)	0.465/42	0.644

The paired *t*-test for the means differences of maternal and paternal scores on the six subscales of the FaMM did not confirm any statistically significant differences between the mean scores.

Additional Analyses

In addition to answering the research questions, additional analyses were conducted on the study data in order to gain greater understanding of the phenomenon of living with a child with asthma. Further analyses of the FaMM instrument were conducted, along with regression analyses of the study variables. The results of these evaluations are presented in this section.

Instrumentation Findings

Confirmatory factor analysis was applied to the FaMM, to evaluate construct validity of the instrument for its use with this study sample of 86 paired participants. While exploratory and confirmatory factor analyses were performed in the development of the instrument, additional confirmatory analyses may be helpful in refining the instrument for future use. Because exploratory factor analysis is aimed at consolidating variables and generating hypotheses, this type of analysis was not consistent with the research aims of the study (Tabachnick & Fidell, 2007). Confirmatory factor analysis was performed and retention of components was performed based on four criteria (Mertler, 2005). First, Eigenvalues were obtained, and 29 components exhibited Eigenvalues above the critical level of 1.0. While evaluation of an Eigenvalue is a reliable criterion for assessing a component, this matrix included 106 items, which is much larger than the recommended 30 variables, and the study sample of 86 is smaller than the recommended 250 participants. The next step in factor analysis was to retain components that account for 70% of the model variance. In this model, 15 components

accounted for 70% of the variance in the model, with the first component accounting for 14.02% of the variance. Using a scree plot for a visual evaluation, there were 25 components that were within the sharp descent and before the elbow of the plot. However, a scree plot is reliable with larger sample sizes, similarly to the Eigenvalues. All of the communalities in the factor analysis were ≥ 0.7 , which is over the critical level of 0.3. Using a varimax rotation, the convergence was 0.989, and the rotation failed to converge, so evaluation of the residuals was not possible. Within the limitations of small sample size, a confirmatory factor analysis was performed and provides information about the clustering of variables and their relationships.

Additional Analyses of Predictive Factors

In order to maintain consistency with the guiding conceptual model of risk and protective factors for family management styles, the predictor variables were categorized as either risk or protective, and distinct models were constructed to evaluate each section of the model separately. This approach also provided more parsimonious models, with less chance for an error related to repeated measures. When all predictor variables were entered into the model as a block, the model had a significance level of $p = 0.104$, $r^2 = 0.302$, adjusted $r^2 = 0.138$. Two of the predictor variables had statistically significant p values, but with large 95% CI's, that decreased the specificity of the model's predictive properties. The specific standardized betas for each of the variables are provided in Table 14 below.

Table 14

Regression Model with all Predictor Variables Included

Variable	Standardized Beta (95% CI)	<i>p</i> value
Child's Age	-0.27 (-2.315, 0.182)	0.092
Child's Gender	-0.13 (-14.424, 5.653)	0.381
Child's Race	-0.142 (-8.708, 3.293)	0.366
Asthma Severity	0.327 (0.417, 20.833)	0.042
Asthma Ed for child	-0.213 (-20.994, 5.659)	0.250
Asthma Ed for parent	0.119 (-7.975, 17.022)	0.467
Either parent have/had asthma	0.107 (-7.264, 14.348)	0.510
Care by specialist	0.358 (0.215, 23.298)	0.031

* $p \leq 0.05$

Next, a reduced model was built with the two predictor variables that had significant p values in the larger model. By eliminating the other variables, the chance of error was decreased, and a more parsimonious model was constructed to describe the phenomenon of normalization, defined as FMS, and operationalized as FaMM scores in families who have a child with asthma. In this reduced model, the $r^2 = 0.204$, adjusted $r^2 = 0.164$, and the model was statistically significant at $p = 0.01$. Asthma severity maintained its statistical significance (Standardized Beta 0.365, 95% CI .256, 21.158, $p = 0.02$); whereas care by an asthma specialist was no longer a statistically significant predictor variable (Standardized Beta 0.241, 95% CI -1.532, 18.29, $p = 0.096$).

While the family FaMM score is an overall representation of normalization for the family, further analyses were performed that investigated the effect of the risk and

protective factors on the subscales of family management styles. The subscales were grouped by their positive or negative correlation with the total FaMM scores.

Specifically, the FaMM subscales that are positively correlated with normalization are: subscale 1/ child's daily life, subscale 2/ condition management ability, and subscale 5/parent mutuality. Conversely, the following FaMM subscales are negatively correlated with normalization: subscale 3/condition management, subscale 4/family life difficulty, and subscale 6/view of condition impact.

Having met the assumptions of regression in earlier analyses, the risk and protective factors were entered as a block into a regression model to evaluate their relationship with the family scores on the FaMM subscales that are positively related with normalization (subscales 1,2, and 5). In this reduced model, none of the predictor variables were statistically significant, and the overall model was not statistically significant ($p = 0.871$, $r^2 = 0.099$, adjusted $r^2 = -0.113$). Next, when the risk and protective factors were entered as a block with the family scores on the FaMM subscales that are negatively related with normalization (subscales 3, 4, and 6), the model was statistically significant ($p = 0.004$, $r^2 = 0.458$, adjusted $r^2 = 0.338$). Specifically, asthma severity was the only predictor variable that was statistically significant in this model (Standardized Beta 0.609, 95% CI .505, .705, $p \leq .0001$).

Analyses Related to Outliers

As discussed earlier, the outlier for the variable asthma severity was included in the analysis because outliers may contain valuable information about the phenomenon of interest. However, from a statistical perspective, it was reasonable to evaluate the

model when the outlier was excluded. When the case that included the asthma severity outlier was excluded from the regression model, the adjusted r^2 was -0.29 and the p value increased to 0 .586, thus losing its statistical significance. Because the FaMM is an instrument that relies on the participants' self-reports of their family management styles, it was consistent with the conceptual underpinnings of the study to include this case in the analysis. Also, based on national prevalence rates, 10% of asthma in children is classified as severe (CDC, 2007); therefore, 2.3% of the study sample was representative of children with severe asthma and were an essential component of the sample.

Summary

In this sample of families who have a child with asthma, the relationships between several risk and protective factors and the family's family management style were measured using the FaMM scale. Of the independent variables, the child's asthma severity was the only variable that showed a statistically significant relationship with family management style. Even though the remaining factors were not significantly associated with the outcome variable, current literature supports their inclusion in studies related to children with asthma.

Because the FaMM is a newly developed instrument, the results of this study provide important foundational data for future studies that utilize the FaMM to quantify family management. Specifically, within the paired parent dyads, five of the six subscales of the FaMM showed a statistically significant correlation, which would be

expected for married couples with a mean length of cohabitation of over 13 years.

While the Cronbach's alpha scores on each of the separate six subscales were below an optimal level, the overall Cronbach's alpha of 0.6 was supportive of the tool's reliability.

CHAPTER V

DISCUSSION

In this chapter, an interpretation of the findings for the results of the data analyses will be provided. Limitations of the study which may have affected the study results will also be discussed. Additionally, innovations for nursing practice and recommendations for future research are presented.

Risk Factors that Impact Asthma Management

Using a risk and protective model to organize the independent variables, the following four risk factors were investigated: child's gender, child's race, child's age, and asthma severity. While only one of the four risk factors exhibited a statistically significant relationship with the dependent variable, family management style, each of the risk factors will be discussed separately in the following sections.

Child's Gender

Because asthma affects males more often than females, it was prudent to investigate the effect of the child's gender on the family's normalization, defined as FMS, and operationalized as FaMM score. Despite having a sample that represented this higher prevalence of asthma among males (55.8%), as compared to females (44.2%), child's gender was not significantly related to the family's management style in this study.

However, the mean age of children in the study (10.18 years \pm 4.29 years) may help to explain this finding. Because children of this age are in a developmental stage before the majority of children have begun to experience puberty, the differences between the genders are not as evident as in adolescence. As the literature review elucidated, there are social stigmas related to having a chronic illness, especially asthma, that are potentially more impactful for males as they adopt traditionally masculine traits in adolescence (Bem, 1993; Iley, 2007). Also, because the treatment regimen for asthma is usually not as complicated as diabetes management, it is not surprising that there was not a difference in family normalization based on child's gender, despite the lower self-reliance for diabetes tasks reported previously (Mansfield, et al., 2004). Furthermore, families may vary on the importance that is placed on the gender of a child and how it impacts their views of the child's illness, and this was not investigated in this study. While the study results do not provide clarity related to gender differences and how chronic illness impacts family normalization, child's gender is an important variable for investigation because of the disproportionate numbers of males who have asthma.

Child's Race

Because there are disparities in health outcomes for minority children who have asthma, especially African Americans, it was important to include minority representation in the study sample, which was achieved despite convenience sampling. In this study, child's race did not have a significant relationship with normalization, defined as FMS, and operationalized as FaMM score. While it was noted that the parents of minority children in this study had high educational levels, authors of a previous study

found that asthma outcomes for minority children did not improve, even when the family's socioeconomic level was as high as that of non-minority children (Miller, 2000). Because there is a relationship between race and health outcomes for children with asthma, it is essential to investigate its impact on normalization, defined as FMS, and operationalized as FaMM score.

Child's Age

In this sample, the children's ages ranged from 3-18, (mean 10.12 ± 4.29), and the variable was normally distributed, which supports generalizability of results to other populations. While there was not a statistically significant relationship between the child's age and normalization, researchers in previous studies have found that the child's age affects how the family deals with the child's illness and its impact on the family (Barton, et al., 2005; Dokken & Ahmann, 2006; Hopia, et al., 2004; Peterson-Sweeney, 2009; Wales, et al., 2007). Ages of children in this sample represented a span of 17 years; this wide range may have inhibited the detection of relationships between the child's age and family normalization, defined as FMS, and operationalized as FaMM score.

Asthma Severity

In this sample, asthma severity showed a significant relationship with normalization and the family's management style; the more severe the child's asthma, the lower the family's FaMM score, which indicates that the family had more disruptions to their daily lives from caring for their child's asthma. While no studies were found that considered

asthma severity and its effect on the family, a study by Dean and colleagues (2010) investigated the effect of a child's uncontrolled asthma on the quality of life for their caregivers and found that work life for the caregivers, along with overall quality of life, was significantly lower when the child's asthma was uncontrolled. Because asthma severity can be controlled with proper treatment, this finding has implications for the importance of tighter control of asthma symptoms, which is often accomplished by following an asthma action plan at home and at school (Borgmeyer, et al., 2005; NHLBI, 2007). Additionally, access to effective preventive care is an essential aspect of adequate asthma control, and parents of children with asthma may need further instruction regarding the importance of preventative care, rather than relying on episodic and emergent care to treat, rather than control, their child's asthma.

Overall, only one risk factor had a significant relationship with normalization; however this variable, asthma severity, can be impacted and potentially ameliorated by effective asthma management by the family that is learned from health care providers. Nurses have the responsibility in fulfilling the educator role to teach the child and family the importance of tight asthma control and preventative care. By focusing on this variable, the child with asthma may have better health outcomes, and the entire family may benefit by having improved normalization and less interruptions to a more *normal* family life.

Protective Factors that Impact Asthma Management

Consistent with the risk and protective model used for inquiry, the following four protective factors were investigated: child's participation in an asthma education program, parent's participation in an asthma education program, parent's past and/or current experience with asthma, and care by a specialist. Even though none of these variables demonstrated a statistically significant relationship with normalization, defined as FMS, each of these protective factors will be discussed in the following sections because based on the literature, these factors have positively impacted asthma outcomes.

Child's Participation in an Asthma Education Program

In this sample, only 16.3% of the children had participated in any type of asthma education program; of these children who received an educational offering, the overwhelming majority (71.4%) participated in only one session. Because educational programs for children with asthma have been associated with positive outcomes, such as: increased school attendance and better school performance (Bartholomew, et al., 2006), increased asthma knowledge (Anderson, et al., 2005; Shaw, et al., 2005), decreased hospitalization rates and emergency department visits (Watson, et al., 2009), and increased quality of life for children and/or caregivers (Shaw, et al., 2005; Watson, et al., 2009), it is reasonable to infer that these positive outcomes may translate into normalization and better family management styles, even though this relationship was not present in this study.

The low rate of participation in an asthma education program for the children in this sample is concerning for several reasons. First, all of the families in this sample had some form of insurance so access to health care services, including patient education from a provider, should not be a barrier to achieving normalization. Next, over half of the children in the study (51.2%) required daily medication for asthma management; therefore, asthma management is a part of daily life for these families and increased knowledge about asthma care self-management may help to decrease stress on the child and promote family normalization. Also, asthma education programs are available in school settings, and only one child in the study sample participated in a school-based program, despite most of the children in the study sample being of school-age. Overwhelmingly, the children in this sample had mild intermittent asthma (90.7%), and the importance of participating in an asthma education program for the child may not be seen as a priority for the parents.

Parent's Participation in an Asthma Education Program

Interestingly, there was a higher rate of participation in an asthma education program for the parents in the sample, with 32.6% of the parents reporting that they had received asthma education. The majority of parents in the sample (81.4% of mothers, 69.8% of fathers) had at least a college education; their rate of participation in asthma education can be interpreted from several different perspectives. First, because these parents are well-educated, they may be more likely to value information about their child's condition and seek out health education from providers. Conversely, the highly-educated parents in the study sample may be more likely to access asthma management

information independently, rather than relying on a formal asthma education program. Also, parents may think that gaining knowledge from asthma education and implementing recommended environmental changes will impose more restrictions on what they consider a normal life for the family. Similar to the Australian fathers of chronically-ill children, who were threatened by increased knowledge about their child's condition (Peck & Lillibridge, 2005), the parents in the study may have perceived that more knowledge about asthma may actually lead to increased stress. Children may participate in an asthma education program that is offered as a part of the regular school day and does not require extra time from the child's daily schedule. However, in order for parents to participate in asthma education, they may have to take time away from work and other responsibilities. Parents would need to perceive that there are positive outcomes from these educational offerings to make the additional time commitment for attendance.

Parent's Past and Current Experience with Asthma

Despite the lack of a relationship between a parent's experience with having asthma and normalization, 30.2% of parents in the study reported having asthma as a child or having a current diagnosis of asthma. Because almost a third of the parents had personal experience with managing their own asthma, they may have felt that they had adequate information to manage their child's asthma, which may explain the low rate of children participating in an asthma education program. While asthma treatment regimens have changed since parents in this study were children, the parents may have developed a sense of self-efficacy, either as children or adults caring for their own asthma condition,

and did not perceive the need for formal asthma education. Recent research into intergenerational asthma by Valerio and colleagues (2010) has investigated the association between parental and child asthma. Those researchers found that children with a parent with asthma were almost twice as likely to have asthma, as compared to children who did not have a parent with asthma (Valerio, Andreski, Schoeni, & McGonagle, 2010). These study findings are supported by the prevalence of asthma in the parents in this study sample.

Care by an Asthma Specialist

In this study, 37.2% of the children received care from an asthma specialist, in addition to care by a primary care physician, but this variable was not significantly related to the family normalization and family management style. While the study sample was comprised of parents who were highly educated and had health insurance, only a little more than a third of the children received care from an asthma specialist. More than half of the children in the sample were on daily asthma medication but were not receiving care from a specialist. This finding may be partially explained by the reported low severity of the child's asthma, based on symptom frequency; however, care by a specialist has been associated with improved health outcomes and parent satisfaction (Chin, et al., 2007; Hopia, et al., 2004; Smedley, et al., 2003). Possibly, the parents in the sample did not recognize the need for specialized care for their child's asthma management and were satisfied with care and information received from primary care sources.

In summary, only one of the risk or protective factors showed a statistically significant relationship with the dependent variable, normalization, defined as FMS, and operationalized as FaMM. However, analyses of the variables and postulating about reasons for the findings based on the sample characteristics has provided valuable information for future studies that will be discussed in the recommendation for future research.

Additional Findings

Parent's Additional Comments

The last question of the Asthma Information Survey was, "Would you like to tell me anything else about your child's asthma?" Of the 43 parent dyads, 24 (55.8%) responded yes to this question and then wrote a short statement about the subject. Some of the parents' quotes are reported in Appendix H and are grouped by the following identified themes: physiologic concerns, changes over time, and emotional concerns. Answers to this question provided valuable insight into the parents' experiences, especially how caring for a child with asthma changes over time. The findings were also consistent with other study findings that caring for a child with asthma may become easier as the child becomes older (Barton, et al., 2005).

Instrumentation Findings

The FaMM was made available online in 2009, by its author, Dr. Knafl, and while the family management style framework has been used in several studies, no published

articles that have used the FaMM were found for comparison with this study. The aforementioned pilot study (Hines & Krowchuk, 2010), *Family Management Styles and Families who have a Child with Asthma*, conducted prior to the current study, provided valuable experience in using this instrument. In this preliminary work, 28 mothers completed the FaMM in face-to-face interviews with the researcher. Based on feedback from the participants in that study, it was determined that the FaMM could be completed easily without the researcher being in attendance for clarification of questions.

In the current study, when preliminary reliability assessments of the FaMM were below a satisfactory level, further testing of the instrument revealed that removing the reverse-coded items resulted in an increased Cronbach's alpha to an acceptable level. Even though all items were included in this study, this further evaluation of the instrument will be shared with its author, along with the study findings.

Evaluation of Eight Dimensions

Insight related to the eight dimensions of normalization has been derived from the study findings. Evaluations of each of these aspects for the study sample are discussed. Overall, the parents in the study had positive views of their children's ability to lead a normal life, both now and in the future. Additionally, parents reported that they felt well-equipped to care for their child's asthma and rated the negative impact of the child's asthma as minimal.

Child identity. In this dimension of normalization, parents are able to focus on the normal aspects of their child (Deatrick, et al., 2006), thereby identifying the child as normal despite having asthma, that may pose a significant threat to the parent's ability to

see their child as having a normal life. Despite the unpredictable nature of asthma, which has been identified as source of stress and anxiety to parents (Jokinen, 2004); the parents in the study were able to view their child with asthma as essentially normal. The findings were consistent with studies that investigated the importance of focusing on the child's abilities, rather than their disabilities in various study populations, such as children with: (a) various chronic illnesses (Knafl & Deatrick, 2002; Wales, et al., 2007), (b) cancer (Deatrick, et al., 2006; Neville, 1998; Ogle, 2006; Simms, 2002), (c) type one diabetes (Hollidge, 2001; Mednick, et al., 2007; Sullivan-Bolya, et al., 2003,) and (d) genetic disorders (Gallo, et al., 2008; Knafl, et al., 2010). In the study, normalization was significantly affected by asthma severity; parents who perceived their child's asthma as severe had more difficulty focusing on the child's normal aspects, thereby decreasing normalization.

In the study, normalization was not affected by the age of the child, which is not consistent with the findings of Barton's 2005 qualitative study, in which parents reported that managing their child's asthma was easier as the child became older. Even though asthma education was not significantly related to normalization, parents and children who learn more about asthma may be able to focus on normal family life because they have the knowledge to prevent and/or manage acute asthma attacks (Barton, 2005).

Illness view. The second dimension of normalization relates to the parents' perceptions of asthma as an illness, including its cause, seriousness, course, and predictability (Deatrick, et al., 2006; Knafl & Deatrick, 2006). The unpredictability of asthma is an established source of stress for parents (ALA, 2010a; Carderelli, 2009;

Jokinen, 2004; Laster, et al., 2009); and therefore, is a threat to normalization. For the parents in this study, their perceptions were consistent with those of the parents in the 2005 study by Barton and colleagues, as they reported an overall positive course for their child's asthma, despite its seriousness and unpredictability. Based on the study findings and the comparison of caregiver burden of other illnesses (Chiou & Hsieh, 2008), asthma management does not pose a significant threat to normalization. For the parents in the study, their perceptions reflect decreased attention on the negative aspects of asthma as an illness; thereby, normalization was promoted for the child and family (Knafl, et al., 1996).

Management mindset. This dimension of normalization is evident in the parents' perceptions of the difficulty of maintaining the treatment routine for the child's illness and has been identified as integral to normalization from the perspectives of parenting and care giving (Deatrick, et al., 2006). Based on the study findings, parents who have a child with severe asthma have more difficulty with their child's daily asthma regimen and this negatively impacts normalization. Based on the NHLBI guidelines for asthma management, a child with severe asthma will require multiple daily assessments of peak flow and medication adjustments based on their status (NHLBI, 2007). Also, severe asthma is characterized by instability, despite daily medication, and often requires emergent care and hospitalization (ALA, 2010a; Jenkins, et al., 2003; NHLBI, 2007). Overall, the parents in the study reported relative ease in caring for their child's asthma, which promotes normalization, and contrasts to difficulties reported by parents in

previous qualitative studies (Englund, et al., 2001; Gallo, et al., 2008; Wong & Chan, 2006).

Parental mutuality. While this dimension of normalization directly relates to the FaMM parent mutuality subscale, it may also be reflected in other subscales, such as parenting philosophy. While the FaMM may be utilized with single parent families to measure normalization, the parent mutuality subscale is specific to married and/or partnered parents. Parental mutuality is a component of normalization, but is not necessary for a family to achieve normalization. Normalization is threatened when there is a lack of agreement between parents regarding their child's illness (Knafl, et al., 1996; Knafl & Deatrick, 2006). However, for the parents in this study, there was a high degree of parental mutuality, which promotes overall normalization. These findings are consistent with those of Simon and Conger (2007), in which parents were found to have similar parenting styles, rather than opposing approaches to parenting. Despite studies that supported differences in parenting between mothers and fathers of infants in the neonatal intensive care unit (Feeley, et al., 2007; Fegran, et al., 2008); this study did not have similar findings. From the perspective of inequalities within families based on gender (Bem, 1993), the differences in responsibilities for caring for a child's asthma were not evident in the parent mutuality dimension of normalization in this study. The parents' highly correlated scores on five of the six FaMM subscales are indicative of a high degree of parent mutuality between the parents in the study.

Parenting philosophy. This dimension of normalization is representative of the parents' beliefs and approaches to illness management (Deatrick, et al., 2006; Knafl &

Deatrick, 2006). While parenting philosophies often vary greatly because they are affected by many factors, such as: culture, religion, personal experience, and individual personalities, it is important for the parents of a chronically ill child to share goals and priorities related to the management of their child's illness. The findings of this study are consistent with studies that identified goal setting as an important step in effective management of a variety of illnesses (Bursch, et al., 1999; Dokken & Ahmann, 2006; Wright & Leahey, 2005). Specifically, an asthma action plan is a method for setting management goals for a child with asthma and is recommended as the current standard of care (ALA, 2010b; Borgmeyer, et al., 2005). Questions on the FaMM relate to setting goals for managing the child's condition and providing a normal family life, directly reflecting this dimension of normalization. Inaccessibility to health care can be an impediment to effective goal-setting (Gupta, et al., 2006; Javier, et al., 2007; Sin, et al., 2003), but because all of the families in the study had health insurance, this factor was not a barrier for the study population. Also current and/or past experience with an illness has been identified as positively influencing effective goal setting (Dokken & Ahmann, 2006; Englund, et al., 2001; Holden, et al., 1998; Wright & Leahey, 2005), and 46.5% of parents in the study reported a personal experience with asthma. Also, parents' goals included providing a normal life for the family may be particularly effective in promoting normalization (Sharkey, 1995).

Management approach. In this dimension of normalization, parents report their perceptions of their abilities to incorporate asthma management routines into daily life without causing major disruptions to normality. The focus is on overall routines, rather

than specific strategies (Deatrick, et al., 2006; Knafl & Deatrick, 2006). Parents in the study reported that they were able to incorporate care for their child's asthma into their existing lifestyles, rather than making multiple changes to family life. These findings are consistent with previous studies, in which families were more likely to be compliant with treatment regimens that were adapted to fit their current situations (Dokken & Ahmann, 2006; Hanson, et al., 2005; Peterson-Sweeney, 2009). Also, parents were able to incorporate necessary changes, such as daily medication, into family routines as part of a new definition of normal family life, which is consistent with the experiences of parents of medically fragile children, who may never fit established attributes of normal life (Rehm & Bradley, 2005). Parents' responses were reflective of positive evaluations of the integration of asthma treatment routines into daily life, thereby promoting normalization.

Family focus. This dimension is reflective of the parents' evaluation of the balance between managing the child's illness and other aspects of family life (Deatrick, et al., 2006; Knafl & Deatrick, 2006). Parents in the study assessed their child's asthma as having a relatively minimal impact on normal family activities. When the family is able to focus on what is normal, rather than abnormal, they are better able to achieve normalization, which is consistent with current research on the potential negative physical and psychological effects of caring for a sick child for all family members (Boling, 2005; Hayman, et al., 2002; Hobfoll & Spielberger, 1992; Hollidge, 2001; Van Horn & Kautz, 2007). Also, the more severe the child's asthma, the more difficult it is for the family to maintain a balance between the child's medical needs and normal family

life, which was evident in the study findings. When the child's illness is consistently rated as a family priority, it is more difficult for the family to achieve normalization.

Future expectations. The last dimension of normalization is a representation of the parents' outlook for themselves and their child and the long-term impact of the child's illness (Knafl & Deatrick, 2003). For the families in the study, their responses to questions on the FaMM that relate to their child's ability to have a normal future are positive and are reflective of successful normalization. The parents' expectations are consistent with the positive long-term outlook for children with asthma to have healthy lives (Jenkins, et al., 2003; Martinez, 2008; NHLBI, 2007; CDC, 2008). Parents in the study did not focus on worries for their child's future, which have a negative effect on the family's current normalization (Knafl, et al., 1996; Ogle, 2006).

Evaluation of FaMM's Six Subscales

Despite overall agreement on the eight dimensions of family management style, when the scores on each of the six subscales are scrutinized, there are some interesting findings. Because each of the six subscales represents a different aspect of caring for a child with an illness, the findings of each subscale will be discussed separately below.

Child's daily life scale. On the 5 items of this subscale, parents responded to statements that evaluate the impact of asthma on their child's daily life. Higher scores on this subscale were indicative of higher levels of normalization for the child. With a subscale range of 5-25 for each parent, the mothers' mean scores (22.79) were slightly lower than fathers' mean scores (23.07), which may indicate that the mothers perceived asthma as having a greater effect on the child's daily life, as compared to the fathers'

perceptions. While the childrearing responsibilities are shared in many American families, responsibility for managing the child's illness often lies with the mother, who may possess greater insight into the stressors of daily needs for asthma management, which may be reflected in the lower scores. Out a possible score of 50 for parental dyads, the parents in this study had a mean score of 45.86, which is indicative that they do not think that asthma negatively impacts their child's daily life. The parents focused on the child's abilities to lead a normal life, as a reflection of the child identity dimension of FMS, and also reported a low impact of asthma on normal family life, which relates to the family focus dimension.

Condition management ability scale. This subscale is another positively scored subscale and with 12 items, the individual parent's scores can range from 12-60. The mothers' (52.56) and fathers' (52.89) mean scores in this study were very close and reflect that both parents feel confident in their abilities to manage their child's asthma. In addition, the mean score for parent dyads is high (105.45/120), based on the possible score. This finding may be related to the high educational levels of the parents in this study (>70% have college degrees or higher), which may translate into knowledge about asthma and a feeling of self-efficacy related to managing their child's asthma. The relatively high rate of participation in an asthma education program for parents (>30%) in the sample may also be related to this finding. Parents reported that the child's treatment regimen was not overly difficult as a reflection of the management mindset dimension of FMS.

Condition management effort scale. This is the first of the three FaMM subscales that are negatively correlated with normalization. Parents responded to 4 items that measure the amount of time and work required to manage their child's illness. With a score range of 4-20, and lower scores indicating normalization, the mothers' mean score (8.07) and the fathers' mean scores (7.42) reflect that asthma does not require them to expend a substantial amount of energy in caring for their child's asthma. Again, the mothers' scores are indicative that they may bear more of the caregiver effort in caring for the child's condition. Because parents reported that caring for their child's asthma changes over time, it is reasonable that this cross-sectional view of management effort represents the present family situation and is not intended to capture changes over time. Also, parents reported that they were effective in their abilities to manage their child's asthma, as a reflection of the management approach dimension of FMS.

Family life difficulty scale. This is another FaMM subscale that measures difficulty with managing asthma from the perspective of how asthma makes the parent's life more difficult. With 14 items comprising the subscale and a range of 14-70, the mothers and fathers in the study had the same mean score on the subscale (18.40), which is very low. Again, this finding may be related to the high educational levels of the parents in the study, and their confidence in their abilities to care for their child. Therefore, these families have the adequate resources to meet their child's daily needs and asthma management is not a source of stress for these families, as it may be for families who are strained by other stressors. The family focus dimension of FMS is also reflected in this

subscale, as parents perceived they were able to maintain normal life, despite managing their child's asthma.

Parent mutuality scale. This is the last subscale that is positively correlated with family management styles and is intended for use only with partnered parents. For the mothers in this study their mean score was slightly lower (32.32) than the fathers' (33.49), which indicated that mothers are not as satisfied with the spousal agreement about the child's care, as compared to the fathers. With an overall possible score of 80 for parent dyads, a mean score of 65.81 indicates that there was a need for increased agreement between parents in the study regarding caring for their child's asthma. This subscale relates directly to the parent mutuality dimension of normalization and FMS.

View of condition impact scale. Lastly, this subscale is negatively correlated with normalization, and the 10 items measure the parent's perceptions of the seriousness of their child's illness. The parent's mean scores were very close, but the mothers have a slightly higher mean score (16.56), as compared to the fathers (16.22), which indicated that mothers reported asthma as a more serious condition both in the present and in their future for their child. The FMS dimension, future expectations, is reflected in this subscale, along with the child identity dimension.

In summary, the mean scores of the mothers and fathers for each of the six subscales were close and were identical on one subscale, indicating agreement within parent dyads about the impact of asthma on the family. The mean scores of the parents were equivalent on one subscale, family difficulty scale. This was a low score, which is inversely correlated with normalization. Interestingly, the mothers' mean scores were

lower on all positively correlated subscales, meaning that they perceived their child's asthmas as having a more serious impact on both the child and family, both in the present and in the futures. Also, the mothers' mean scores were higher on the subscales that indicated more difficulty managing their child's asthma, which may infer that mothers perceive they are bearing an unequal burden in care giving responsibilities.

Properties of the FaMM

The study findings are supportive of the use of the FaMM to operationalize normalization and to quantitatively measure FMS in families who have a sick child. First the post-hoc Cronbach's alpha results for summative maternal and paternal FaMM scores were at or above an acceptable level of 0.7. Also, the parent dyads in the study were able to complete and return the instrument without contacting the researcher for clarification of questions. Additionally, the statistically significant correlation between parents on 5 of the 6 subscales is evidence that the FaMM is consistently measuring the parents' perceptions of normalization in mothers and fathers. The instrument exhibited acceptable psychometric and usability properties in this study.

Study Limitations

While this study has generated knowledge for nurses who care for children with asthma and their families, there are several limitations that will be discussed in this section. First, the study used a cross-sectional descriptive design. The parents' perceptions of normalization as operationalized in the FMS were measured at one point

in time. From the parents' narrative responses, it is evident that the care demands of a child with asthma are a dynamic phenomenon and longitudinal research is needed to capture these changes over time. Next, the study sample was comprised of a convenience sample from one geographic area and may not be representative of children who have asthma and live in other areas of the U.S. Additionally, parents who agreed to participate in the study may be different from other parents of children with a child with asthma who were not a part of the sample. Some of the mothers had participated in the researcher's previous study, had exposure to the FaMM instrument, and were obviously motivated to share their experiences as the parent of a child with asthma. Generalizability is constrained by the higher educational levels of the study participants, but may be applied to parents with similar educational resources.

Also, the study included only married parent dyads, which is not representative of many family configurations in the U.S. This sample is not representative of family management for single parent families, which comprise 15.3% of White and 49.8% of African American U.S. ("Family structure and children's living arrangements: Percentage of children ages 0–17 by presence of parents in household and race and Hispanic origin, 1980–2009," 2009). Surveys were completed by the participants without the supervision of the study investigator; and therefore, the environmental conditions were not controlled. Despite these identified limitations, the study does have generalizability to families with well-educated parents who have access to health care for their children.

Contributions to Nursing Knowledge

This study provides several contributions to nursing knowledge. First, it provides a model for studying families and their responses to having a sick child. The conceptual model that was developed for the study included specific asthma risk and protective factors and their impact on family normalization. The model could be altered to study another condition, such as diabetes. The impact of diabetes specific risk and protective factors on family normalization could be measured. Both acute and chronic conditions can be investigated through this conceptual lens, and longitudinal changes in families could also be investigated.

Next, asthma severity was identified as a risk factor for decreased normalization for families in the study. Of the 7 million U.S. children with asthma, approximately 10% or 700,000 children have severe asthma (ALA, 2010a; CDC, 2007). These children and their families are at increased risk for difficulties that affect the entire family by not being able to have a normal family life. Importantly, no previous studies have identified asthma severity as a predictive factor for family normalization.

While parents' perceptions of normalization were related, mothers and fathers in the study had different perceptions related to the impact of their child's illness on the family. Mothers reported that asthma has more negative effects on family normalization, as compared to fathers. Even though the differences in parents' perceptions were not significantly different, the results support that parents have dissimilar views about caring for their child with asthma, and feel differently about the overall effect on the family. Lastly, non-White families in the study sample did not have a significantly different

FaMM score, as compared to White families. This finding may indicate that the health disparity among children with asthma is decreasing when families have access to care by a specialist and educational resources. These factors may moderate the effect of asthma on family normalization and need to be tested in future studies. Knowledge generated by this study may be foundational for future studies that investigate normalization in families.

Innovations for Nursing Practice

Despite the lack of significant relationships between most independent variables and the dependent variable of normalization, this study provides several innovations for nursing knowledge. Parents reported the mercurial nature of asthma, which may be responsible for changes in parent's perceptions about caring for their child's condition over time. Attention should be focused on families who care for a child with severe asthma and the need for intensified interventions to help them normalize their family situations. While it was a logical inference that having a child with more severe illness is related to difficulty providing a normal family life, the study results offer statistical evidence that these families are experiencing difficulties with achieving high levels of family normalization. In the current healthcare climate of limited time and resources, it is imperative that nurses identify families who are at risk and target interventions toward those children and parents.

In the study sample, the racial representation of the general population was closely approximated. Also, despite the lack of a significant relationship between participating in

an asthma education program and higher FaMM scores, asthma education programs continue to flourish and report positive outcomes related to improved school attendance, increased asthma knowledge, and decreased emergency department visits for asthma care (Indinnimeo, et al., 2009; Watson, et al., 2009).

Based on the study finding that gender of the child was not significantly related to the family's FaMM score, it may not be necessary to be gender-specific in asthma education and support for families who have a child with asthma. However, based on the child's mean age in the study, there may be developmental considerations that would support individualizing the child and family asthma education based on gender. Specifically, adolescent boys may have concerns related to limited participation in stereotypically-male activities due to asthma exacerbations or girls may be concerned about the social stigma of rescue inhaler use in social situations. Issues such as these were not evident in this study primarily because there were few adolescents in the study sample.

The utilization and psychometric evaluation of the FaMM instrument are also considered innovations that have resulted from this study. Analyses of the instrument are vital to its development and future refinement. While the six subscales of the FaMM are useful for investigating the various aspects of family management styles from a specific perspective, it would be helpful if the overall FaMM score was representative of the family's level of normalization. Also, because the Cronbach's alpha for the three subscales that represented difficulty in family management were higher than those that represented positive aspects of family life, this may mean that parents find it easier to report what is challenging for them regarding caring for their sick child, rather than

reporting their positive perceptions. Because the FaMM instrument measured both positive and negative aspects of caring for a chronically ill child, it may not be necessary to have 18 reverse coded items. When the instrument was administered in face-to-face interviews in the pilot study, the mothers did not have any questions related to completing the FaMM. The investigator's electronic mail and telephone number was provided on the instruments that were distributed, and no contacts were made by study participants to ask questions about completion of either the AIS or FaMM.

Recommendations for Future Research

The recommendations for future research are presented from several different perspectives. First, the author proposes variables for inclusion in studies that investigate families who have a child with asthma. Next, implications for application of the family management styles framework are discussed. Lastly, recommendations are provided from the broader perspective of children and family health.

Families with a Child with Asthma

Because asthma is the most common chronic illness in children, and the prevalence of this disease is increasing, it is prudent for nurses to gain knowledge about the impact of asthma on the child and family. For this study, family was narrowly defined, and single parent families did not meet the inclusion criteria. In future studies, different family configurations should be included and mixed linear regression analyses applied to the data (Knafl, et al., 2009). Based on the high response rates to the opportunity to provide

more information about caring for a child with asthma, it can be inferred that parents are willing to share their experiences of asthma management for their child. Also, based on these comments, the experience of caring for a child with asthma changes over time; therefore, longitudinal studies that follow families over several years may provide essential information and insight into this phenomenon.

Family Management Styles Framework

After evaluating several conceptual models to provide a foundation for this study, Family Management Styles Framework was chosen and became an irreplaceable underpinning for inquiry. This framework has been applied successfully with several different patient populations, and based on this author's experience, is recommended as an appropriate lens through which to study the impact of illness on families. The FaMM instrument provides the researcher with a user-friendly instrument with which to quantify and measure family management styles. Measuring changes in the family's normalization over time using the FaMM may offer knowledge about the times of increased need for intervention for families who have a chronically ill child. By evaluating each of the six subscales within the FaMM, researchers are afforded more specificity in evaluating the various aspects of daily family life that are affected. The eight dimensions of the family management styles can also be better understood by using this framework with different populations.

Child and Family Health

It is appropriate to include both the child and family in studies that ascribe to a perspective of family-centered care. However, it is recognized that adequately defining the term family can be an impediment to the inclusion of families in research studies. It is recommended that a broad definition of family be applied to future studies that investigate the health of children. While the FaMM is not intended for completion by children, it would be beneficial to include the child's perspective in studies, as their input is also valuable. It would also be helpful to include the perspectives of other family members, such as siblings and extended family living in the same household with a child with asthma to gain insight from these perspectives.

Summary

This descriptive study has identified asthma severity as a factor that affects the family management styles of families who have a child with asthma. Parents in the study completed an instrument that provided information about certain risk and protective factors, along with the FaMM, which is a quantitative measure of family management styles. While the parents' responses regarding the impact of their child's asthma on the family were correlated, there were differences between the mothers' and fathers' perceptions when the six subscales were analyzed separately. Overall, the mothers in the study reported that asthma decreased the family's ability to have a normal daily life and required time and effort to manage their child's condition. The family management styles framework provided an appropriate lens for studying this phenomenon and is

recommended for use with future studies that investigate families and how they care for chronically ill children.

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APPENDIX A

IRB APPROVAL LETTER



THE UNIVERSITY of NORTH CAROLINA
GREENSBORO

OFFICE OF RESEARCH COMPLIANCE
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Federalwide Assurance (FWA) #216

To: Heidi Krowchuk
Parent-Child Health (Nursing)
316 Moore Building

From: UNCG-IRB

Authorized signature on behalf of IRB

Approval Date: 6/09/2010
Expiration Date of Approval: 6/08/2011

RE: Notice of IRB Approval by Expedited Review (under 45 CFR 46.110)
Submission Type: Initial
Expedited Category: 7.Surveys/interviews/focus groups
Study #: 10-0213

Study Title: Parental Perceptions of Family Management Styles in Families with a Child with Asthma

This submission has been approved by the IRB for the period indicated. It has been determined that the risk involved in this research is no more than minimal.

Study Description:

The purpose of this study is to 1) measure the maternal and paternal perceptions of family management styles of families who have children with asthma; and 2) determine the effect of specific risk and protective factors on family management styles.

Regulatory and other findings:

This research meets criteria for a waiver of written (signed) consent according to 45 CFR 46.117(c)(2).

Investigator's Responsibilities

Federal regulations require that all research be reviewed at least annually. It is the Principal Investigator's responsibility to submit for renewal and obtain approval before the expiration date. You may not continue any research activity beyond the expiration date without IRB approval. Failure to receive approval for continuation before the expiration date will result in automatic termination of the approval for this study on the expiration date.

When applicable, enclosed are stamped copies of approved consent documents and other recruitment materials. You must copy the stamped consent forms for use with subjects unless you have approval to do otherwise.

You are required to obtain IRB approval for any changes to any aspect of this study before they can be implemented (use the modification application available at <http://www.uncg.edu/orc/irb.htm>). Should any adverse event or unanticipated problem involving risks to subjects or others occur it must be reported immediately to the IRB using the "Unanticipated Problem/Event" form at the same website.

CC: Annette Hines, Chris Farrior, (ORED), Non-IRB Review Contact, (ORC), Non-IRB Review Contact

APPENDIX B
RECRUITMENT FLYER

**MOMS AND DADS WHO HAVE A
CHILD WITH ASTHMA**
Opportunity to participate in a research study

Study Purpose: To better understand the impact of asthma on families

Who may participate?

- Parents of a child (ages 1-18yrs.) diagnosed with asthma
- Parents must be at least 18 years old
- Both parents live in the same home with the child who has asthma
- English-speaking

What you will do: Complete 2 surveys about caring for your asthmatic child.

You will receive a \$10 gift card to Wal-Mart after both parents complete surveys.



If you are interested, contact:

Annette Hines, RN

PhD student: The University of North Carolina Greensboro
704-337-2369 or abhines@uncg.edu

APPROVED IRB

JUN 09 2010

APPENDIX C.

LETTER TO ACCOMPANY SURVEYS

Study Cover Letter

Dear Participant,

This is a research project to help nurses learn more about how to help families who have a child with asthma. The project title is Family Management Styles and Families with a Child with Asthma, and the project director is Dr. Heidi V. Krowchuk, RN, PhD, FAAN. We are asking you to take part, since you are a parent (or a step parent) of a child with asthma who has no other chronic illnesses or developmental delays and who lives with you. You will be asked to answer questions on surveys about your experience with your child's asthma. You may complete the surveys privately and return them to Ms. Hines in the enclosed pre-addressed and stamped envelope. The questions can be answered in less than 30 minutes. You can contact the doctoral student researcher, Annette Hines at 704-337-2369 or abhines@uncg.edu, or the project director, Dr. Krowchuk at 336-334-4899 or Heidi_Krowchuk@uncg.edu, if you have any questions or concerns about the project.

The Institutional Review Board at the University of North Carolina at Greensboro has determined that participation in this study poses minimal risks to participants. Some people may find talking about their child's asthma stressful. The researchers will be happy to talk with you at any time if you feel this way. If the questions make you feel stressed, you are to stop answering the surveys immediately and call Annette Hines at 704-337-2369.

If you have any concerns about your rights, how you are being treated or if you have questions, want more information or have suggestions, please contact Eric Allen in the Office of Research Compliance at UNCG at (336) 256-1482. Questions, concerns or complaints about this project or benefits or risks associated with being in this study can be answered by Dr. Heidi Krowchuk who may be contacted at 336-334-4899 (Heidi_Krowchuk@uncg.edu).

There are no costs to you, and you will be given a \$10 gift card for Wal-Mart after you return the completed surveys and the enclosed address card. Participants may benefit from this study by talking about their experiences with their child's asthma. This study may help health care providers to better understand how families manage when they have a child with asthma, and how providers can help them.

All information will be stored in a locked file cabinet in the office of Annette Hines at Queens University of Charlotte in Charlotte NC for 3 years after the project has been completed, and then will be destroyed by shredding. The information will be identified only by code numbers. All data files used for analysis will be password protected and will have de-identified coded information only. Only the research team will have access to these files. All information obtained in this study is strictly confidential unless disclosure is required by law.

You have the right to refuse to participate or to withdraw at any time, without penalty. If you do withdraw, it will not affect you in any way. If you choose to withdraw, you may request that any of your data which has been collected be destroyed unless it is in a de-identified state. If significant new information relating to the study becomes available which may relate to your willingness to continue to participate, this information will be provided to you.

By completing and returning the enclosed surveys, you are agreeing that you have read this letter and you fully understand the contents of this document and are openly willing consent to take part in this study. All of your questions concerning this study have been answered.

Thank you,
Annette Hines

UNCG IRB
Approved Consent Form

Valid 6/9/10 to 6/8/11

APPENDIX D
INSTRUMENTS

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APPENDIX D.1

ASTHMA INFORMATION SURVEY

Asthma Information Survey

Please answer the following questions about your child who has asthma, yourself, and your family. Answer each question completely. Place an X in the box or write out your answer. You may use a pen or pencil. Please contact Annette Hines at abhines@uncg.edu or 704-337-2369 if you have a hard time filling out this questionnaire.

1. Age of child who has asthma: _____ years
2. Child's gender male female
3. Child's race Asian American African American Other
Hispanic American White
4. How many other children are living in your home? _____
5. Does your child take asthma medication every day? Yes No
 - a. If yes, what is the name of the medication? _____
6. Does your child receive health care from an asthma specialist in addition to your pediatrician?
Yes No Not sure
7. Does your child have health insurance?
Yes No If yes: Private SCHIP Other
8. How often does your child have asthma symptoms? (Mark all that apply)
Less than 2 days/week Less than 2 nights/week More than 2 days/week
More than 2 nights/week Over 3 nights/week Daily symptoms
9. Has your child participated in an asthma education program? Yes No Not sure
 - a. If yes, where was the program held? Doctor's office Child's school
Health department other
 - b. How long was the program? 1 session 1-3 sessions
4-6 sessions over 6 sessions

10. How long have you and your partner/spouse lived together? _____

11. Is the mother the biological parent of the child with asthma? Yes No

12. Is the father the biological parent of the child with asthma? Yes No

13. Did either parent have asthma as a child?

a. **Mother:** Yes No b. **Father:** Yes No

14. Does either parent have asthma as an adult?

a. **Mother:** Yes No b. **Father:** Yes No

15. Has either parent participated in an asthma education program?

a. **Mother:** Yes No Not sure If Yes, answer b and c below.

b. If yes, where was the program held? Doctor's office Child's school
Health department other

c. How long was the program? 1 session 1-3 sessions
4-6 sessions over 6 sessions

d. **Father:** Yes No Not sure If Yes, answer e and f below.

e. If yes, where was the program held? Doctor's office Child's school
Health department other

f. How long was the program? 1 session 1-3 sessions
4-6 sessions over 6 sessions

16. What is each parent's highest level of education?

a. **Mother:** some high school high school graduate
 some college college graduation graduate study

b. **Father:** some high school high school graduate
 some college college graduation graduate study

17. Is there anything else you would like to tell me about your child's asthma? Yes No

If yes, please write in the space below and continue on the back if needed.

APPENDIX D.2

FAMILY MANAGEMENT MEASURE



FAMILY MANAGEMENT MEASURE

Kathleen Knafl, PhD
Janet Deatrick, RN, PhD
Agatha Gallo, RN, PhD
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FAMILY MANAGEMENT MEASURE

This questionnaire is about how your family manages caring for a child with a chronic condition.

INSTRUCTIONS

For each statement in this questionnaire, you are asked to rate your response to the statement on a scale of 1 to 5, with 1 indicating "Strongly disagree" and 5 indicating "Strongly agree". Please respond to each statement in this questionnaire based on what you think, not on how you think others might respond. If your child has more than one chronic condition the word "condition" refers to all of their diagnoses together. Also, many of these questions use the word "family". This refers to those people living in your household that you think of as family.

Section 1: to be completed by everyone
Please check the boxes with your answers.

	Strongly Disagree 1	2	3	4	Strongly Agree 5
1. Our child's everyday life is similar to that of other children his/her age.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Our child's condition gets in the way of family relationships.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Our child's condition requires frequent visits to the clinic.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. In the future we expect our child to take care of the condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Our child enjoys life less because of the condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Taking care of our child's condition is often overwhelming.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Our child's condition is like a roller coaster with lots of ups and downs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Our child's condition is the most important thing in our family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly Disagree				Strongly Agree
	1	2	3	4	5
9. It is very hard for us to take care of our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Our child takes part in activities he/she wishes to despite the condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Because of the condition, we worry about our child's future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Our child's condition doesn't take a great deal of time to manage.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. We have some definite ideas about how to help our child live with the condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Despite the condition, we expect our child to live away from home in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. We have enough money to manage our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Our child is different from other children his/her age because of the condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. It is difficult to know when our child's condition must come first in the family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. We are looking forward to a happy future with our child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. When something unexpected happens with our child's condition, we usually know how to handle it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Our child's friendships are different because of the condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. We expect to be devoting less time to our child's condition in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. A condition like the one our child has makes family life very difficult.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Our child's activity rarely interferes with other family activities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Our child's condition requires frequent hospital stays.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly Disagree				Strongly Agree
	1	2	3	4	5
25. We feel we are doing a good job taking care of our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. People with our child's condition have a normal length of life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. It's often difficult to know if we need to be more protective of our child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. We often feel unsure about what to do to take care of our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Our child's condition will be harder to take care of in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. We think about our child's condition all the time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. It seems as if our child's condition controls our family life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Many conditions are more serious than our child's.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. It is hard to get anyone else to help us with our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. We have not been able to develop a routine for taking care of our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. It takes a lot of organization to manage our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. We are sometimes undecided about how to balance the condition and family life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. It is hard to know what to expect of our child's condition in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. Even though our child has the condition, we have a normal family life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. Our child would do better in school if he/she didn't have the condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. We are confident that we can take care of our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly Disagree				Strongly Agree
	1	2	3	4	5
41. We have goals in mind to help us manage our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. It is difficult to fit care of our child's condition into our usual family routine.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. Dealing with our child's condition makes family life more difficult.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. We know when our child needs to be a child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. A condition like the one our child has makes it hard to live a normal life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

This ends Section 1.

Section 2 covers aspects of family management when there are adult partners in a household. The term "partner" refers to a spouse or partner living in the same household. If you currently have a partner, please proceed to the next page. If you do not have a partner, please stop here.

Section 2

The questions in the next section relate to you and your partner. For each statement in this section, rate your response to the statement on a scale of 1 to 5, with 1 indicating "Strongly disagree" and 5 indicating "Strongly agree". Again, please respond to each statement in this questionnaire based on how YOU feel, not on how you think your partner or others might respond.

	Strongly Disagree 1	2	3	4	Strongly Agree 5
46. We are a closer family because of how we deal with our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47. My partner and I have different ideas about how serious our child's condition is.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48. I am pleased with how my partner and I work together to manage our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
49. My partner and I argue about how to manage our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
50. My partner and I consult with each other before we make a decision about our child's care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
51. My partner and I have similar ideas about how we should be raising our child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
52. I am unhappy about the way my partner and I share the management of our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
53. My partner and I support each other in taking care of our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

APPENDIX E

SAMPLE DEMOGRAPHIC AND ASTHMA-RELATED INFORMATION

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Table E.1

Description of Study Sample: Child's Age (N = 43)

Variable	Min	Max	Mean	Frequency	Percentage
Child's age	3	18	10.18 (\pm 4.29)		
3				2	4.7%
4				2	4.7%
4.5				1	2.3%
5				2	4.7%
6				2	4.7%
7				4	9.3%
8				3	7.0%
9				4	9.3%
10				4	9.3%
11				3	7.0%
12				4	9.3%
13				2	4.7%
14				1	2.3%
15				2	4.7%
16				4	9.3%
18				3	7.0%

Table E.2

Description of Study Sample: Demographic Characteristics (N = 43 parent dyads)

Variable	Frequency	Percentage
Child's Gender		
female	19	44.2%
male	24	55.8%
Child's Race		
White	34	79.1%
Asian American	3	7.0%
African American	5	11.8%
Other	1	2.3%
Number of Siblings in Home		
0	8	18.8%
1	24	55.8%
2	6	14.0%
3	3	7.0%
5	1	2.3%
Mother is biological mother		
Yes	40	93.0%
No	3	7.0%
Father is biological father		
Yes	39	90.7%
No	4	9.3%
Mother's Highest Educational Level		
Some high school	0	0.0%
High school graduate	2	4.7%
Some college	6	14.0%
College graduate	19	44.2%
Graduate study	16	37.2%

Variable	Frequency	Percentage
Father's Highest Educational Level		
Some high school	1	2.3%
High school graduate	1	2.3%
Some college	11	25.6%
College graduate	16	37.2%
Graduate study	14	32.6%

Table E.3

Asthma Severity and Management (N = 43 parent dyads)

Variable	Frequency	Percentage
Asthma Severity		
Mild Intermittent	39	90.7%
Moderate Intermittent	3	7.0%
Moderate Persistent	0	0.0%
Severe	1	2.3%
Child requires Daily Asthma Medication		
Yes	22	51.2%
No	21	48.8%
Child Receives care by Asthma Specialist		
Yes	16	37.2%
No	27	62.8%
Either Parent Has Asthma Currently or as a Child		
Yes	20	46.5%
No	23	53.5%
Mother Had Asthma as a Child		
Yes	8	18.6%
No	35	81.4%
Mother Currently has Asthma		
Yes	13	30.2%
No	29	67.4%
Missing	1	2.3%
Father Had Asthma as a Child		
Yes	5	11.6%
No	38	88.4%
Father Currently has Asthma		
Yes	2	4.7%
No	40	93.0%
Missing	1	2.3%

APPENDIX F

SCATTERPLOTS OF RESIDUALS

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Figure F.1

Scatterplot of Residuals for Child's Gender and FaMM Family Score

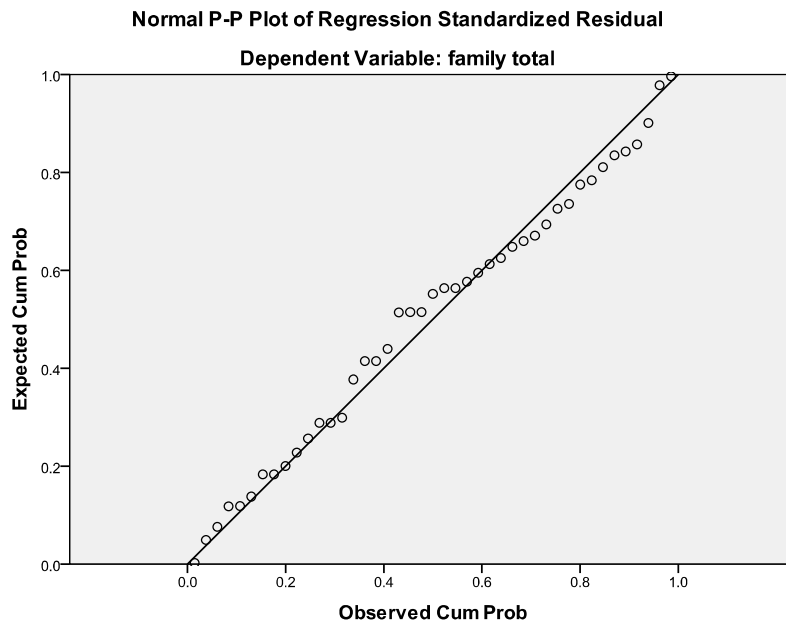


Figure F. 2

Scatterplot of Residuals for Child's Race and FaMM Family Score

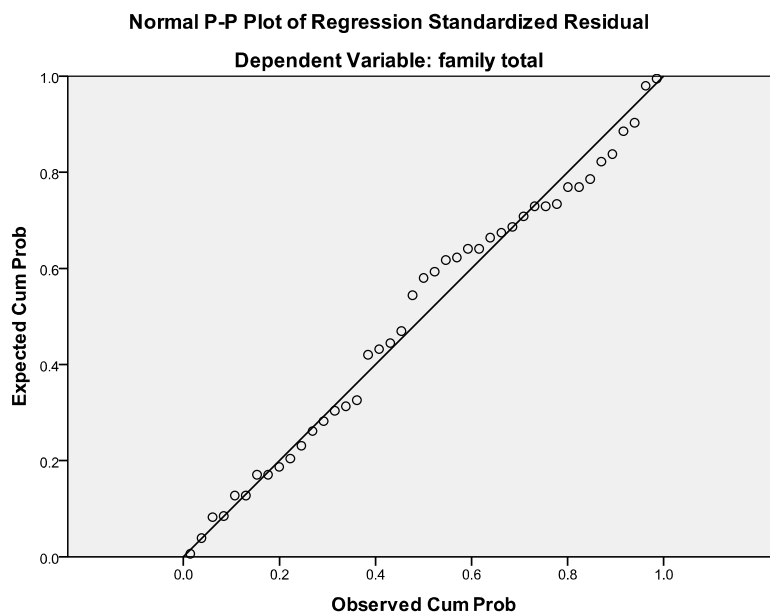


Figure F.3

Scatterplot of Residuals for Child's Age and FaMM Total Score

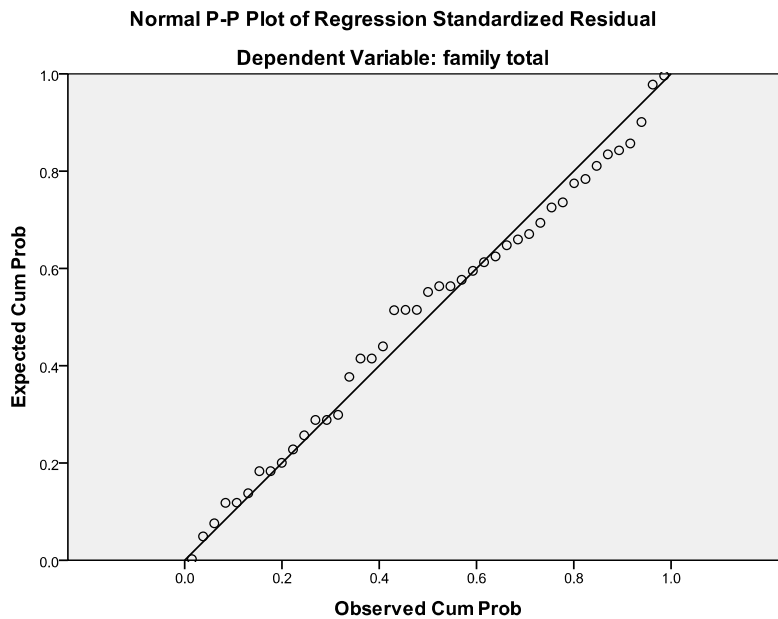


Figure F. 4

Scatterplot of Residuals for Asthma Severity and FaMM Total Score

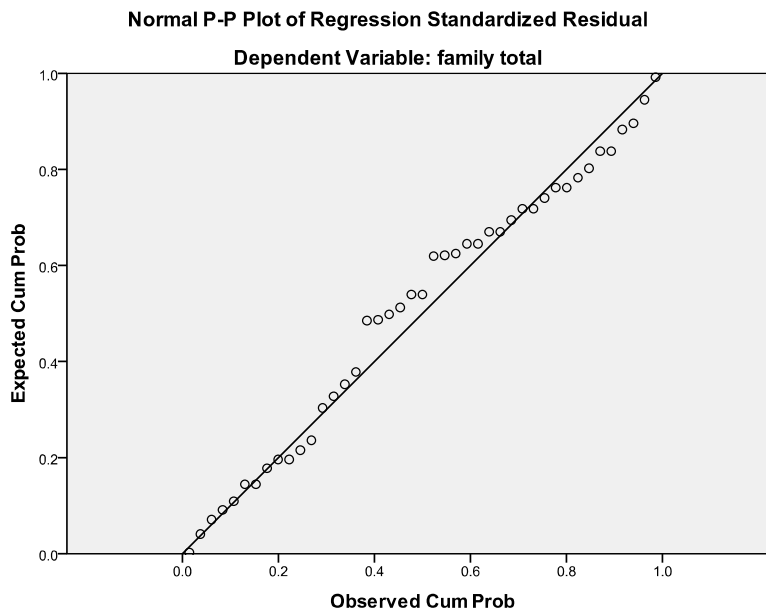


Figure F. 5

Scatterplot of Residuals for Child's Asthma Education and FaMM Family Score

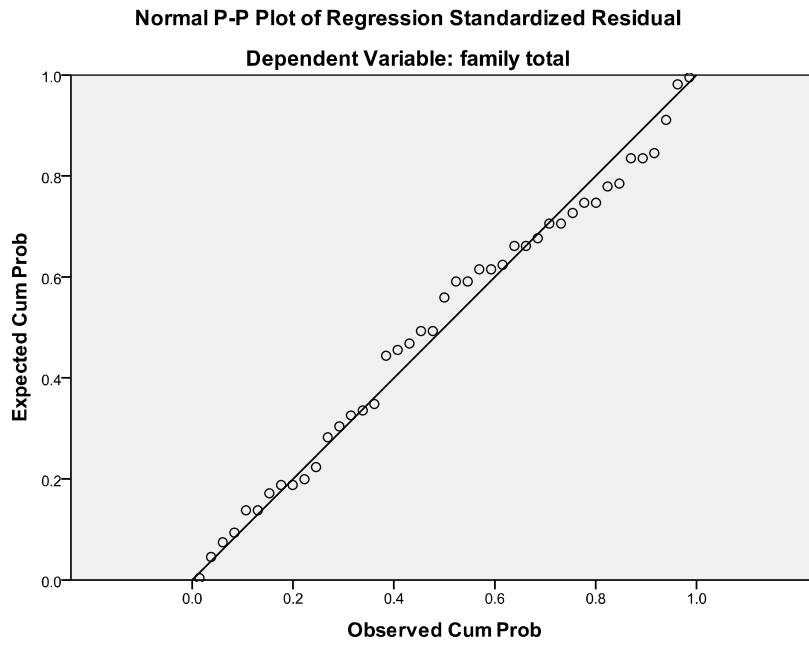


Figure F. 6

Scatterplot of Residuals for Parent's Asthma Education and FaMM Family Score

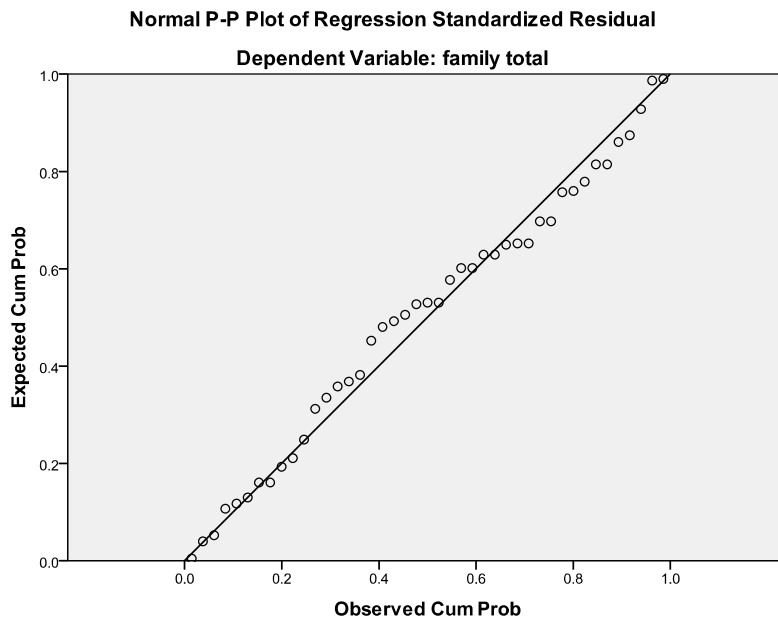


Figure F. 7

Scatterplot of Residuals for Parental Asthma and FaMM Family Score

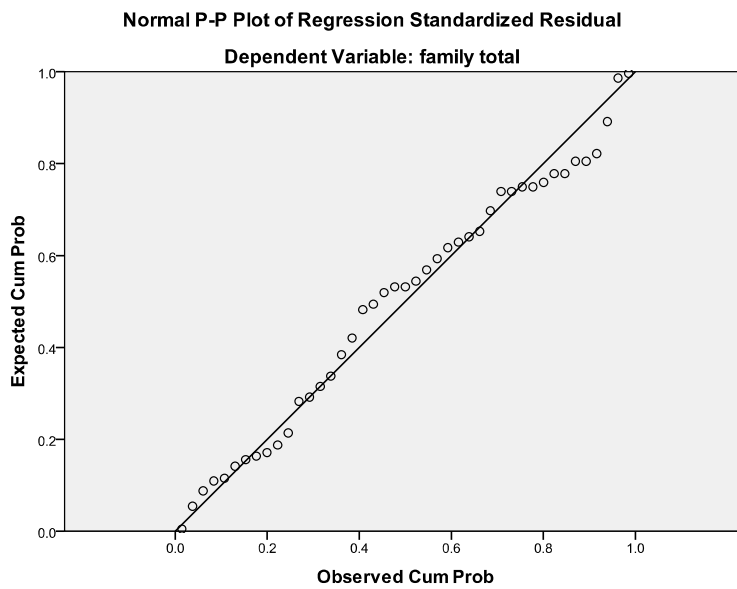
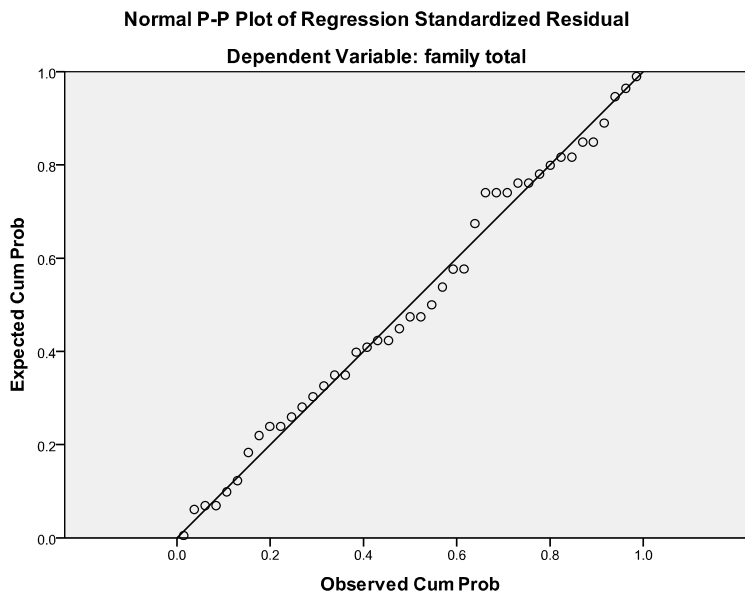


Figure F. 8

Scatterplot of Residuals for Asthma Specialist Care and FaMM Family Score



APPENDIX G

HISTOGRAMS

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Figure G.1

Histogram of Maternal FaMM Scores

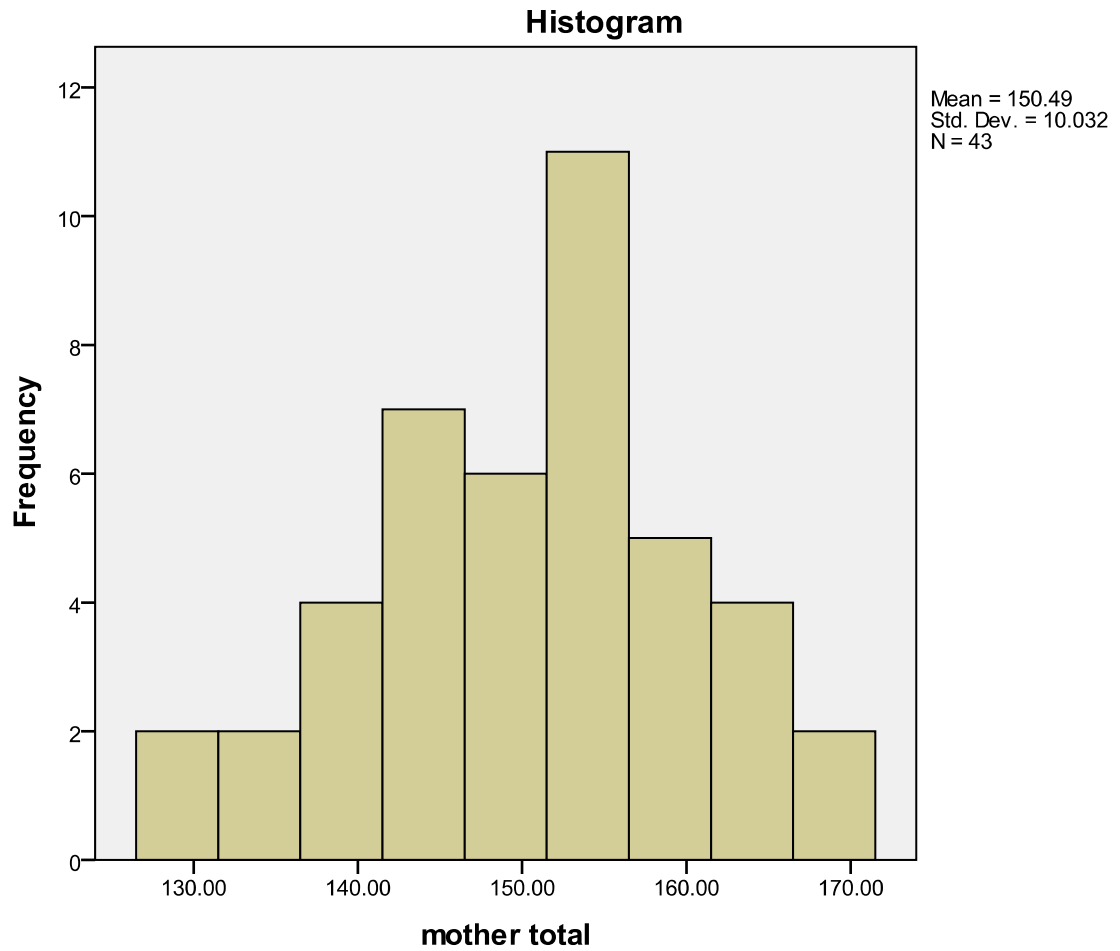


Figure G.2

Histogram of Paternal FaMM Scores

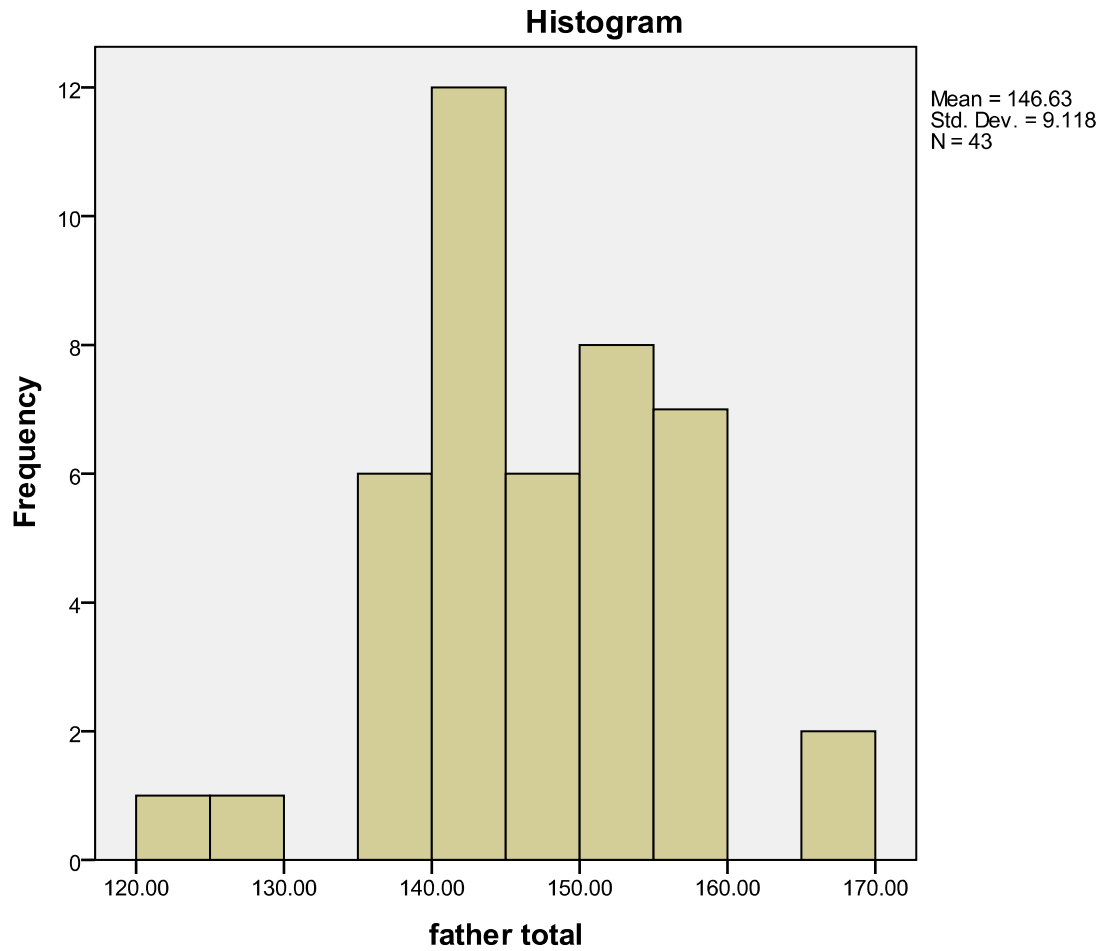
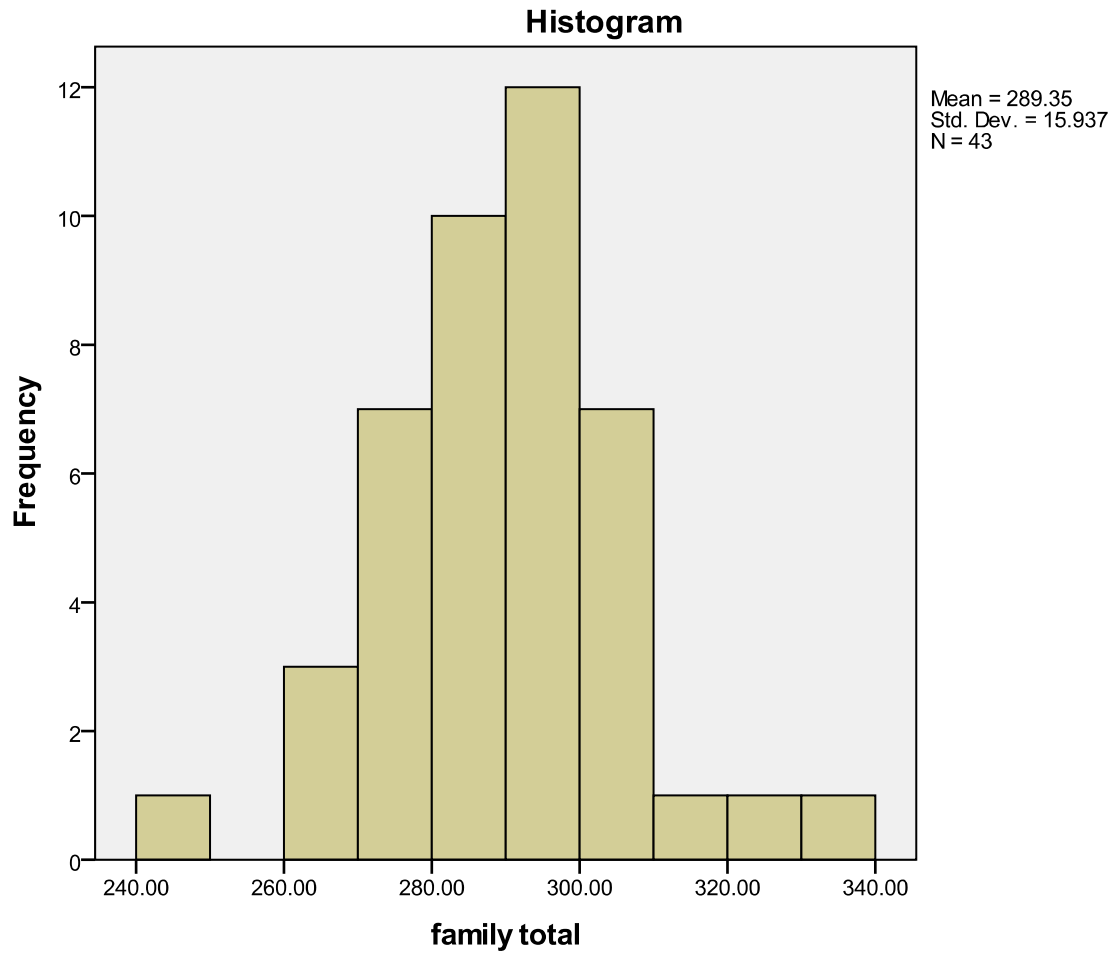


Figure G.3

Histogram of Family FaMM Scores



APPENDIX H

SAMPLES OF PARENT'S STATEMENT RESPONSES

Table H

Samples of Parent's Statement Responses (n = 43 parent dyads)

Physiologic Concerns
“Carriers inhaler during sports”
“When attack begins, prednisone/nebulizer”
“Asthma is triggered by exertion (exercise) or weather/environment.”
“Concerned about how child will recognize episodes while she is away at college.”
“Attacks happen primarily at night or in extremely hot-humid times.”
“Primarily exercise/seasonal allergy induced”
“Seems to be more active at night, also brought on by emotion. Sometimes needs inhaler playing sports.”
“His condition is pretty stable and under control.”

Emotional Concerns
“The information I received is confusing. At first we were told he was too young to diagnose. Then husband was there when asthma medicine was prescribed. Wife asked if child has asthma, Dr. said “yes” and “use medicine everyday”.
“He’s the oldest of three and the only one with asthma at this time. He is also the only one with other allergies to foods and environment.”

Changes over time

“Those first 6 years were stressful (I had two boys who had croup off/on) running nebulizer treatments around the clock”

“Originally (early condition) his condition impacted family life/”normal” activities for him.”

“His asthma has gotten worse in the last 2 years”

“Initially was on daily medication, but has been medication free for 1 year.”

“His asthma has gotten better over the years. His asthma is mainly in the winter or when the weather changes.”

“When he was first diagnosed, we went to an asthma specialist, however once we knew more about the disease, we went back to just the pediatrician for care.”

“Once we discovered his food allergies, his asthma got much better.”

“Daughter diagnosed at age one year with asthma. Now only has flare-ups with cold/flu/virus.”

“Our child’s asthma is much less severe than it was when he was younger. Our answers would have been different two years ago when we have 2 ER visits in one season.”

“Our daughter’s asthma has somewhat improved as she has gotten older.”
